CHILDREN COPING WITH A SERIOUS ILLNESS

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Abstract

A solid empirical base is needed to expand our understanding of coping in children who are seriously ill. The six studies reported were designed to describe the ways seriously ill children cope with their illness and treatment, and to explore factors (both individual and familial) which influence their coping. The choice of instruments and design were influenced by the Lazarus and Folkman transactional model of stress and coping (1984), especially their concept of coping. In the first study the Kidcope Checklist (Spirito *et al.*, 1988) was adapted to a younger British sample by adjusting the language and by producing a colour coded response sheet. Validity and test-retest reliability were established. In the five hospital based studies 53 children (7-16 years) and their parents took part. All the children had leukaemia or aplastic anaemia. Children's coping was examined in detail by applying a variety of research methods, which included *observation* during a medical procedure (Observation Scale of Behavioural Distress and coping behaviour), a *questionnaire* about children's perception of competence and self-worth (Self-Perception Profile for Children) and a semi-structured *interview* about their coping strategies (Kidcope). Parental coping and the social environment of the family were studied through Coping Health Inventory for Parents and the Family Environment Scale. Results show that the children's coping was significantly related to the context of the problem (everyday-life difficulty, illness related and medical treatment) but much less to the individual differences (sex, age, experience with the illness and self-esteem). Children who rated themselves at interview as more distressed during the blood test were observed to show more distress behaviour; this validated the distress assessment of Kidcope. Children who were observed taking an active interest in the blood test displayed less distress behaviour and had higher self-esteem than children who showed no interest in the procedure. Results from parents and the family are discussed with reference to the children's self-reported and observed coping. Some relationships were found between parents' coping with their child's illness, the social climate of the family and the children's way of coping. The findings contribute to our understanding of children's coping processes and help to bridge the gap between theory and research.

To my father Robert Scheuring

who always believed in me

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Coping is a multidimensional and conceptually complicated process. Research on children's coping needs to establish a solid empirical base, while at the same time criticising and formulating theories. Currently, there is little literature that deals with children's coping, and research which does deal with seriously ill children's coping is even more limited. Given this lack of research literature, empirical studies are needed to validate research instruments for studying how paediatric patients cope and to establish individual and contextual factors associated with it.

It is not the intention of this chapter to provide a complete overview of children's coping but to allow the reader to sample dominating issues and controversies. The chapter confronts the inevitable conflict between theory driven conceptualisations and field based methodology while focusing on children coping with illness. With the exception of Section 1.1, research related to adults is excluded but has been reviewed many times in the past (e.g. Aldwin, 1994; Lazarus, 1993a, 1993b; Pearlin, 1991; Cohen, 1987; Thoits, 1983, 1991; Billings & Moos, 1981, 1982).

The conceptual framework of this thesis was influenced by the work of Lazarus and Folkman (especially by their concept of coping) as discussed in their book *Stress, Appraisal and Coping* (1984). Before describing the framework, earlier approaches to the study of coping will be outlined.

1.1 Early approaches to stress and coping

Coping is a reaction to stress and although coping is a familiar term in everyday use, the provision of an all embracing operational definition is difficult. However, clarity of definition is fundamental to the methodological issues of measurement. Definitions vary according to the theoretical framework, which in turn largely determines the research design.

According to Cox (1978) there are at least three different ways of defining the term *stress*. Two of these have been termed *stimulus-based* (used by engineers) and *response-based* (used by clinical practitioners and physiologists). The stimulus-based stress approach treats stress as a harmful or aversive characteristic of the environment in which individuals find themselves - for example, sound levels (excessive noise) or hours of restraint (animal studies) - and assumes that certain situations are stressful irrespective of individual differences and cognitions. The response-based approach on the other hand defines stress in terms of the physiological response of an individual to aversive stimuli. In these early approaches the term 'coping' was restricted to occasions when a response or a reaction to a stressor was considered to have produced a successful outcome.

A conceptually more demanding definition of *stress* is the one which refers to stress as a process. The *process* definition takes account of the way individuals realise and identify stressors, their reaction to those stressors and how they attempt to cope with them. The process model of stress usually combines psychological and psycho-physiological perspectives, and attempts to identify the structural characteristics of the stressor in terms of the demands made on the person. The purpose of the identification of the stressor's structural characteristics is to enable the appropriate support and resources of an individual to be marshalled in response to that stressor,

and implies an element of cognition, i.e. the thinking which underlies the coping process and sets it in motion.

Having said that coping is a reaction to stress, it may involve either direct action such as avoidant or escape behaviour, or aggressive or compliant behaviour, or it might involve cognitive efforts, i.e. problem-focused or emotion-focused, or a combination of cognition and direct action.

1.1.1 The response-based paradigm

In the 17th century, Descartes put forward the proposition of a fundamental dualism between mind and body. The mind was believed to engage in abstract thought and language, quite separate and distinct from the operations of the body. This Cartesian dualism has long been a cornerstone of the reductionist paradigm underlying the biological sciences (Aldwin, 1994). It assigns the study of the physiological workings of the body to science, and the consideration of the mind and soul to philosophy. Descartes further assumed that the mind and the body were influenced by completely different factors and that very little communication occurred between the two.

Cannon (1939) hypothesised that any threat resulted in a fight-flight reaction and that such a reaction was a general response to any stress - physical or social. Selye's (1956) expanded on Cannon's fight-flight proposal and attempted to characterise an organism's response to continuous stress in terms of what has been called the General Adaptation Syndrome. This theory is *physiologically based* and is substantiated through studies involving stressors, in this case harmful physical stimuli such as mechanical trauma or the injection of foreign substances, which created physiological changes. Selye (1991) concluded that the biological reactions he observed, represented the response of the body to stressors, i.e. a coping response, and were

objective indicators of stress which Selye defines as a general bodily response to any demands made upon the body.

The range of stressors was extended through *animal studies* including events which caused arousal as a result of novelty, uncertainty or unpleasantness but not necessarily a physical threat or challenge (Hennessy & Levine, 1979 in Rutter, 1981). Similarly, human studies where adults had to cope with a variety of life events, for instance, examinations, parachute jumping and admission to hospital have also been undertaken (Cox, 1978). At first the results of these studies, where physiological responses were measured, appear to be reasonably consistent, yet work with parents of children dying of leukaemia (Wolff, Friedman, Hofer & Mason, 1964) and children admitted to hospital for tonsillectomy (Knight, Atkins, Eagle, Evans, Finklestein, Fukushima, Katz & Weiner, 1979) has shown subsequently that some individuals failed to exhibit the expected physiological changes and lead to the idea that coping differs according to emotional responses within a given situation.

Although there is little disagreement with the explanation of the biological processes involved in coping, the validity of such non-specific concepts of stress and coping has been widely questioned. Nevertheless in two recently presented papers immunological changes resulting from daily stress were monitored (Kipp-Campbell & Gunnar, 1996; Spangler, 1996). Using salivary cortisol sampling these researchers assessed children's coping with potentially stressful situations in natural settings - in the classroom and in the home. This marked a return to assessments of physiological changes stemming from coping with an everyday stressor, in one case a study involving children in day care in America, and in the other a lasting life change, children starting primary school in Germany.

The traditional approaches to stress and coping emerged from two separate and distinct bodies of literature, namely animal experimentation as mentioned above and

psychoanalytic ego psychology as discussed in Section 1.1.2. In the former approach experimental psychologists investigated coping as escape and avoidance learning by an animal faced with a threatening stimulus. The animal model focuses on the concept of drive (arousal or activation) and portrays coping as a behaviour response which controls aversive conditions, lowering drive and excitement (Miller, 1980). In other words, if the underlying theoretical model is based on the animal model, coping is equivalent to performing adaptive tasks *successfully*, that is to say the *outcome* of coping is observable.

The stimulus- and response-based concepts of stress and coping are now considered inadequate to assess an individual's coping, and interactive models have been developed which tend to focus on the individual's dynamic relationship with the environment, and emphasise the critical importance of perceptual-cognitive processes and of individual differences (Lazarus, 1976, cited in Cox, 1978). The new theories treat stress and coping not so much as a 'stimulus' or a 'response' but more as a process. The stimulus and response definitions are uni-dimensional, and it will be argued later, are of limited use in describing coping (Figure 1.1).

1.1.2 Stable and predictable characteristics

In *the psychoanalytic ego psychology model*, coping is defined as realistic and flexible thoughts and acts which solve problems and thereby reduce stress. According to Lazarus and Folkman (1991) the main differences between the treatment of coping in this model compared to the animal model is the focus on ways of perceiving and thinking about an individual's relationship with the environment. Although behaviour is not ignored, it is treated as less important than cognition.

The earliest psychoanalytic interest in defense centred on psychopathology as a characteristic style of an individual for managing threat. A theory which greatly

influenced personality and clinical psychology was that each form of psychopathology was associated with a specific defensive style (e.g. hysterical neuroses to repression; paranoia to projection). According to Lazarus (1993b) the link between forms of psychopathology and particular defense is more a conceptual ideal than a clinical reality.

The work of Haan and Vaillant (1977 and 1969 respectively, in Lazarus 1993b) was derived from a developmental psychoanalytic framework. When the concept of coping was formulated within the tradition of psychoanalytic ego psychology, it was not only concerned with behaviour but also with cognition. The processes used by people to manage troubled relationships were examined and it was found that the criteria for evaluating coping within the theoretical model of ego-psychology were concerned with recognising reality and keeping to it (Haan, 1977).

Research and measurement approaches based on the ego-psychology models tend to assess coping traits and coping styles rather than coping processes. They view coping structurally as a style or traits rather than as a dynamic ego process. Coping *traits* refer to stable, predictable characteristics of an individual, that is to say a person behaves as he usually behaves without being influenced by the environment in which the stressor occurs. Defined in this way coping *styles* are similar to traits. They both refer to the enduring qualities in an individual which serve an explanatory role in accounting for regularities and consistencies in thought and behaviour. This model, unlike the transactional model described in Section 1.2, assesses *outcome* and assumes the coping mechanism to be fairly *stable* within individuals and across contexts (Figure 1.1).

The trait and style approaches are limited in scope. Measures of coping traits and coping styles have been shown to be poor predictors of actual coping processes and

tend to underestimate both the *complexity* and the *variability* of the ways individuals actually cope (Lazarus & Folkman, 1984).

As will be discussed in this thesis, to be concerned with change is to be concerned with *process* as opposed to *structure*. Structure refers to stable factors such as individual differences including self-esteem or locus of control (Moos & Billings, 1982) or static features of the environment (Monat & Lazarus, 1991). Even though the importance of the notion of process in the stress and coping literature has been written about time and time again (e.g. Mechanic, 1991; Perlin, Lieberman, Menaghan & Mullan, 1981) research questions have tended to emphasise the stable, structural properties of the person or the environment. In the adult literature studies of coping have focused on coping traits (e.g. Goldstein, 1973; Chan, 1977) and social support (e.g. Monat & Lazarus, 1991). Social support, for example, is believed to be a mediator or buffer between stress and health, and is usually described in terms of the relatively stable size and characteristics of an individual's social network.

However, Folkman and Lazarus (1985) comment:

> 'Structural approaches such as these do not provide information about whether a person actually copes, seeks or uses social support, or actually feels supported in a particular stressful encounter. Furthermore, structural approaches cannot reveal changes in stress-related phenomenon, including emotion, as a specific encounter unfolds or from encounter to encounter.'

1.1.3 Summarizing the three coping models

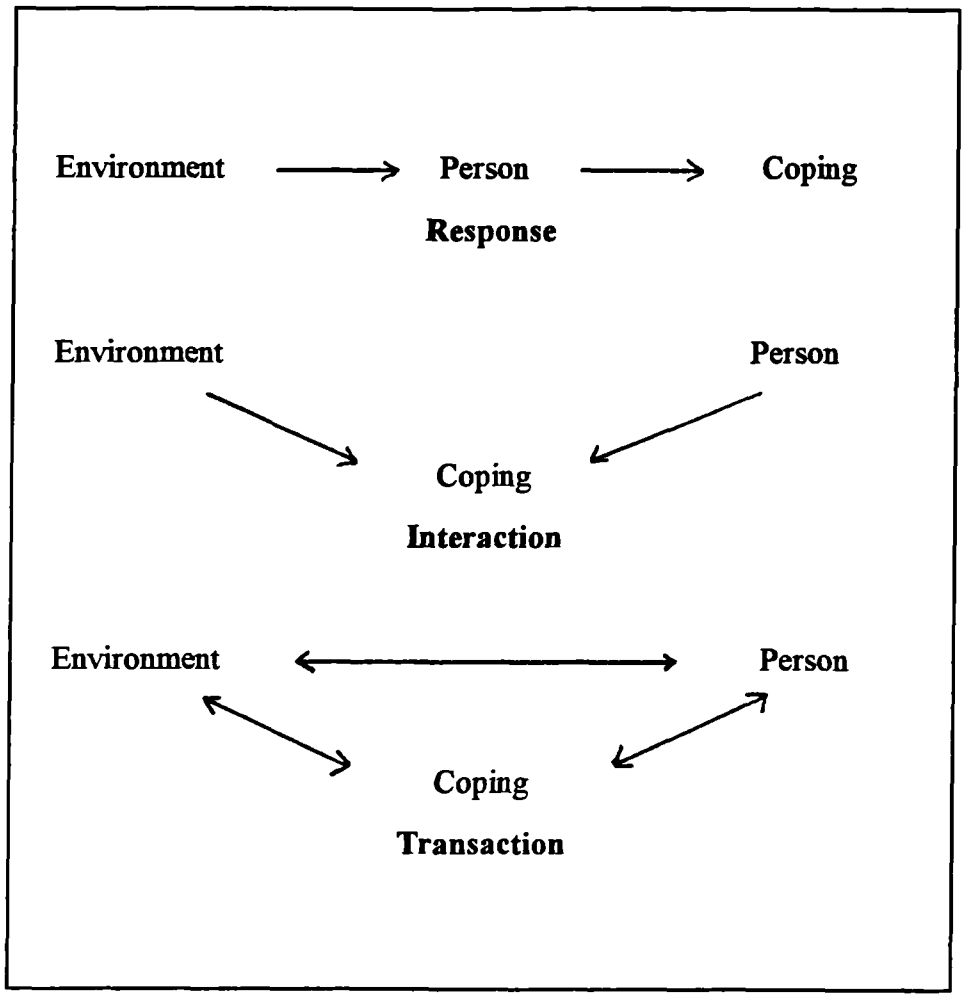

Figure 1.1 An illustration of the three models of coping

Figure 1.1 represents the *stimulus-response* model of stress and coping. In this model coping behaviours are viewed as simple responses to stressful environmental stimuli. In the *interactionist* model coping is hypothesised to be a function of the individual and environmental characteristics. The coping strategies and the coping behaviours the individual uses may be influenced both by *personal characteristics* as well as *the type of stressor* or environmental demands. And finally, the *transactional* model described in Section 1.2. considers transactions only within the context of a

single stressful situation. Here, the person and environmental variables influence appraisal, which in turn determines the way of coping.

1.1.4 Assessing the three coping models

Traditionally psychology has relied on four basic research techniques. First, research questions were answered through *experimental* or laboratory-based techniques where the stimulus and the expected response are clearly defined and measured in a specified or controlled setting. Second, other research has answered questions using *'paper and pencil'* tests. In this type of research psychometric properties such as internal and test-retest reliability are critical and external validity is often tested against other paper and pencil instruments. The third technique is the *observational* method where researchers record what the individual does at a given point in the laboratory or in a real-life situation. The recordings are made in a systematic way often relying on predetermined behaviour categories. And finally *qualitative* research studies what people actually think and do in real situations and is mainly used by clinicians and qualitative ecologists. These researchers conduct field studies through observations and interviews relying upon simple coding techniques to make sense of the information gathered.

There is a consensus among researchers that coping is a crucial variable in understanding the effect of stress on physical and mental health and general well being, yet researchers disagree on how it should be measured. Ongoing discussions, certainly in the adult literature, fuel the controversy between assessing the *coping styles,* thought to be stable characteristics of individuals, and *coping processes*, fluctuating strategies that change in response to the person and/or the environment. For example, should the content of coping items on a questionnaire be *general* enough to apply to a variety of situations or should they be *specific* to particular situations? Should the rich and *complex* descriptions of coping strategies or the

simplified dimensions that are thought to underlie more complex characteristics be assessed, and should coping scale items be used to assess coping effort or simply dichotomous items to indicate whether or not a particular coping strategy was applied when dealing with a stressor?

The methods used in any particular research design must surely depend on the questions asked. Therefore, whether specific or general coping strategies are assessed, whether this is done through self-report or observational methods, and whether the design is cross-sectional or longitudinal depends entirely upon the aim of the study.

1.2 The transactional model of stress and coping

A transactional model by definition combines an active person with an active environment. Transaction means that not only does the environment affect the individual, as in the stimulus-response sequence, but also that the individual affects the environment; both influence each other during an encounter. The action of an individual changes reality, which in turn affects the behaviour and emotional state of the individual. Outcomes, therefore, are the result of the interplay between the individual and the context across time in which the state of one affects the state of the other in a continuous dynamic process.

The Lazarus and Folkman transactional model (1984), which underlies the cognitive theory of stress and coping, looks at the individual and the environment in a mutually reciprocal, bidirectional way.

1.2.1 Coping: the definition

The term *coping* implies a reaction to stress irrespective of whether the stressor is a minor or a major event. Coping is thought to be an important mediator of the experiences which shape an individual's development. It influences subsequent vulnerability and resilience in different situations.

Richard Lazarus and Susan Folkman (1984) define coping as:

> 'Constantly changing cognitive and behavioural efforts to manage specific external and/or internal demands appraised as taxing or exceeding the resources' (p.144).

This definition highlights three characteristics of coping: first, it is *process-oriented* in that it refers to what the individual actually thinks or does. The changes which occur in these thoughts and actions adapt to an unfolding, altered situation. Secondly, the definition is *contextual* and related to what an individual thinks or does within a specific context. Thus coping is determined not only by personal qualities but by the individual's assessment or judgement of the demands of a particular situation. The contextual approach highlights specific stressful situations as opposed to general stressful conditions. Finally, Lazarus and Folkman define coping without reference to its *immediate outcome* and without reference to a result or a visible effect. They consider coping as the efforts made by an individual to manage the situation and are not concerned with the 'success' of these efforts.

1.2.2 Coping: a theoretical framework

The way children with a serious illness cope forms the basis of this thesis. Although, coping is at the heart of the transactional model (Lazarus & Folkman, 1984) and its

theoretical framework, coping is only *one* of the elements which make up the model - the others being stress, appraisal and reappraisal.

The 'position' of coping in the stress and coping cycle is illustrated by Figure 1.2 and discussed in the following three sections.

1.2.2.1 Stress

Stress is an inevitable aspect of everyday life, however it has only recently been systematically conceptualized. The differences in human functioning lie not only with the stressors encountered but also in the way individuals cope with stress. As reported in the adult literature (e.g. Monat & Lazarus, 1991; Lazarus, 1993; Aldwin, 1994) the interaction between a person and the environment corresponds to the contemporary medical concept of recovery from illness.

A more realistic way of looking at this latest approach is to explore the relationship and interaction between an individual and the environment while taking into account the characteristics of that individual and the nature of his or her environment. As a model of stress and subsequent *coping*, the interaction forms an important part of this thesis and will be considered in detail.

In Lazarus and Folkman's model, for example, illness is no longer seen as being caused by an external organism only; whether or not an illness occurs depends on the susceptibility of the individual. Equally there seems to be no objective way of predicting psychological distress as a reaction to a stressor without reference to a person's characteristics. These characteristics include age, sex, temperament or self-esteem as well as family background and previous experience with a given situation.

Psychological stress - emotional, social and cognitive - stems from the interaction of people and their environment. This interaction is evaluated, consciously or unconsciously, by the individual. If the result of the assessment is found to be taxing and going beyond his or her existing resources, the coping mechanism is then set into motion. It can therefore be said that psychological stress is the result of the assessment or judgement of a particular person-environment relationship and is subjected to cognitive appraisal.

1.2.2.2 Appraisal and reappraisal

Appraisal refers to the evaluation, judgment or assessment of cognitive processes. It is these cognitive processes which intervene between the stressor and the reactions that lie between stress and coping. Through the cognitive appraisal process the individual evaluates, consciously or subconsciously, the significance of what is happening and what action needs to be taken.

The stressor is reappraised *after* coping and is then either set to rest, which is to say that the problem has been solved, or is appraised once more. This procedure is illustrated by Figure 1.2. Reappraisal refers to an altered appraisal based on new information from the environment and/or the person. At this stage of the process the original stressor, even if not set to rest, has invariably changed.

According to Lazarus (1981) emotional responses or distress are specific to the appraised significance of the stressor. It is this differentiation between emotional responses that leads to the quality, as well as the intensity, of the emotional and problem focused responses. For example, the vulnerability or resilience of an individual (Rutter, 1981) is closely related to appraisal. Vulnerability is easily conceptualised in terms of coping resources; a vulnerable person's coping resources

are likely to be deficient whereas a resilient person, with better coping resources, may find the same situation less stressful.

Some of the early work on psychosocial stressors assumed that life-events could be studied without reference to their meaning to the individual. This view, however, is no longer held by most investigators (Rutter, 1981). Depending on the resilience of an individual, the same situation may be perceived by different individuals as either irrelevant, or benign and positive, or threatening and harmful. Resilient children may defy expectation by recovering from or coping successfully with significant life stresses and develop into well-adapted individuals. According to Fonagy, Steele, Steele and Higgitt (1994) characteristics that appear to protect children from stress include IQ and problem solving, task related self-efficacy, autonomy, a sense of self-worth, interpersonal awareness and empathy as well as planning abilities and a sense of humour - findings largely supported by Masten, Best and Garmezy (1990). They found that children who experience chronic adversity fare better or recover more successfully when they have a positive relationship with a competent adult, when they are good learners and problem-solvers, are engaging to other people, and have areas of competence and perceived efficacy valued by self or society. Much productive work has also been done on resilience and vulnerability by Rutter, 1979, 1981; Garmezy, Masten & Tellegen, 1984; Garmezy, 1985 and others. However the Lazarus and Folkman (1984) model does not take account of an individual's history and vulnerability factors except to the extent that coping is determined not just by personal qualities but by the individual's assessment or judgement of the demands of a particular situation, thereby highlighting specific stressful situations as opposed to generally stressful conditions.

It can be said therefore that the route taken by a person to cope is influenced by his or her resources. These may include individual differences, such as health and energy, existing commitments, problem solving skills, social support or material

resources, and the history of previous experience with stressful situations and the way he or she coped with them.

As discussed above, appraisal forms part of the process through which the individual assesses a person-environment relationship or situation (primary appraisal). This process also evaluates the resources and options for changing that relationship (secondary appraisal). Primary appraisal and secondary appraisal converge to shape the meaning and emotional quality of each encounter. Cognitive appraisals and reappraisals are not necessarily conscious, nor are the factors which shape appraisal always easily recognised or understood. The environment and personal factors are interdependent (Lazarus & Folkman, 1984). The significance of appraisal and reappraisal in stress and coping is derived from the operation of cognitive processes that give weight to one within the context of another. As Figure 1.2 shows, when the individual is exposed to a stressor, the stressor is appraised and, subject to the stressor being assessed as stressful, the coping mechanism is set in motion.

1.2.2.3 Coping

Coping has at least two major functions: to manage or alter the stressor that is causing the distress (problem focused coping), and to regulate the emotional response to the stressor (emotion focused coping). Problem and emotion focused coping influence each other throughout the stressful encounter. They can assist and/or obstruct each other (see Figure 1.2 for a visual explanation). In general, problem focused forms of coping are more helpful when the stressor is perceived as susceptible to change. On the other hand, emotion focused forms of coping are more frequently relied upon when the stressor is perceived as more or less constant.

Problem focused forms of coping include cognitive problem solving and decision making, interpersonal conflict resolution, information gathering, advice seeking,

time management and goal setting. Problem focused coping strategies are used when the stressor is likely to be controlled and resolved. Emotion focused forms of coping include cognitive efforts that change the appreciation of a stressor without changing the environment; for example looking on the bright side of things, or making behavioural efforts to make oneself feel better. Emotion focused coping strategies are used to manage situations associated with an uncontrollable stressor. However, in this thesis the distinction between these two functions did not form part of the research questions.

Coping can affect the individual directly, psychologically, socially and physiologically. The psychological effects include emotional reactions such as anxiety or depression, whereas the social effects may include changes in interpersonal relationships with peers, siblings or parents. The physiological effects are known to reveal themselves through changes in body temperature or blood pressure. However, stress at the social level does not necessarily mean that it will also be experienced at the psychological or physiological levels. If it should be, then it may be experienced in a different way. The critical link among the three levels is the cognitive appraisal discussed earlier.

No single coping strategy can be classed as either strictly problem-focused or strictly emotion-focused. Coping strategies fluctuate between the two kinds according to the situation in which a stressor is dealt with. Furthermore, no single coping strategy can be judged as 'better' or 'worse' than another. The term coping is used whether the process is adaptive or nonadaptive, successful or unsuccessful, consolidated or fluid and unstable. Coping should be regarded as efforts to manage stressful demands whatever the outcome. Judgement (appraisal) as to the suitability of a coping strategy is made according to each stressor. Denial and 'denial like behaviour', for example, may be appropriate in one situation but not in another.

As discussed above the *effectiveness of coping* does not form part of this model. Lazarus and Folkman (1984) freed the concept of coping from judgement of effectiveness, and as a result of their work any effort an individual makes in reaction or response to a stressor is now termed 'coping'. However, its omission will be criticised in Chapter 10 and more specifically in Section 10.5.

Coping should not be compared with 'mastery over the environment'. Many sources of stress cannot be mastered and under these conditions, therefore, effective coping is that which allows the person to tolerate, minimize, accept or ignore what cannot be mastered.

A popular prayer states:

> 'God grant me the grace to accept things I cannot change, courage to change the things I can, and wisdom to know the difference.' Amen

To summarize the theory of coping which guides this thesis, coping refers to changing cognitive and behavioural efforts and attempts to manage specific demands that are assessed as taxing and exceeding the resources of the individual (Lazarus & Folkman, 1984).

The way an individual feels about a stressor does have a role to play in the concept of coping, for example in the psychoanalytic theory of stress and coping. However, in this thesis coping is based on the Lazarus and Folkman (1984) model which is concerned with an individual's cognitive and behavioural efforts. As emotion does not form part of this model it was not possible to consider it in detail but it has been considered by Werner and Smith (1982), Garmezy and Rutter (1983) as well as Lazarus (1991).

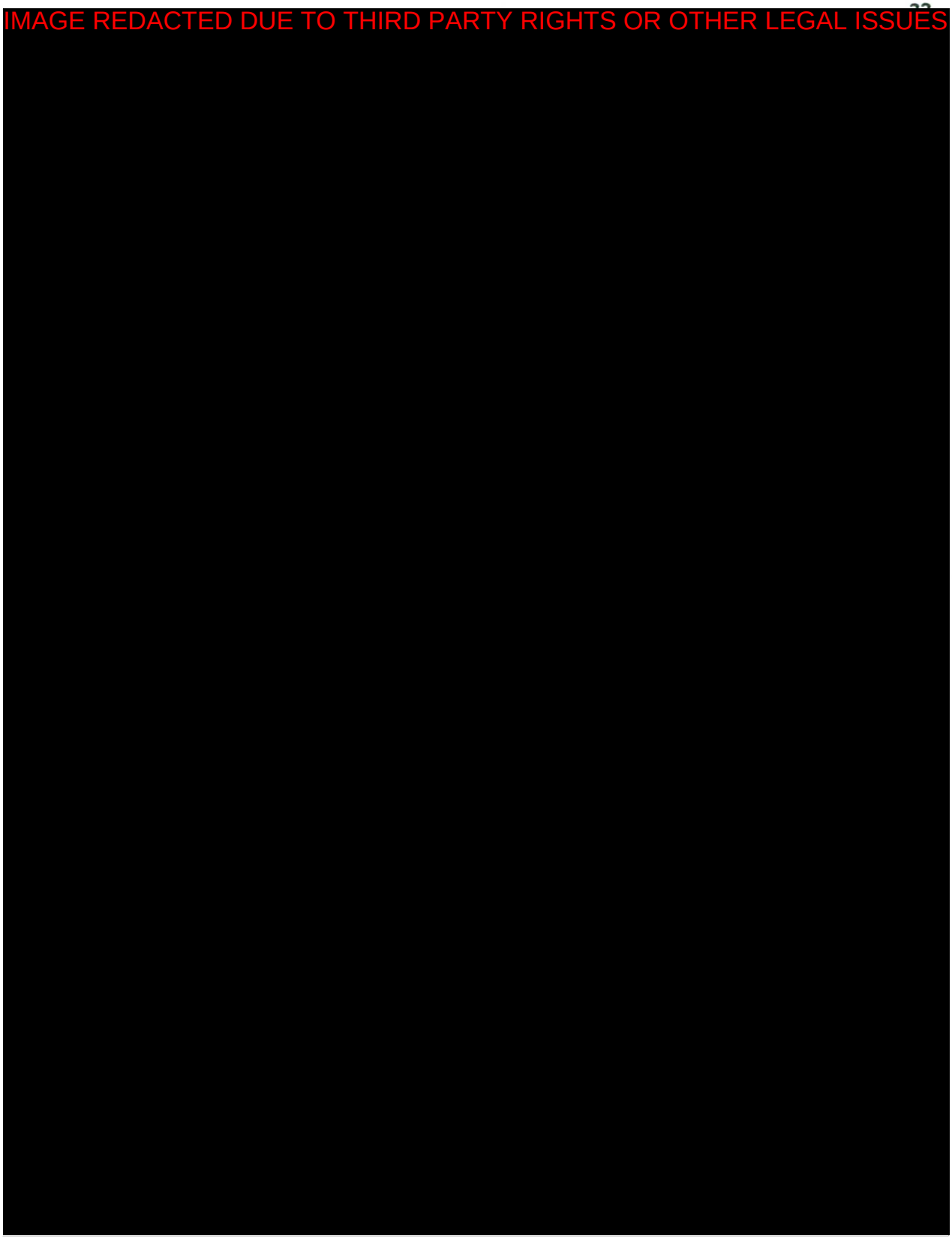

Figure 1.2 Stress and coping model

(Folkman, Chesney, Mckusick, Ironson, Johnson & Coates, 1991)

Some researchers argue that coping is best assessed as a set of observable behaviours. Others dispute this suggestion, arguing that coping is an internal process best evaluated through self-report measures (La Greca, Siegel, Wallander & Walker, 1992). In this thesis both methods will be used to explore the way ill children cope.

1.3 Self-report method based on the transactional model

Research on children's coping processes has been heavily reliant on the approach adopted with adults. Current literature on adult coping tends to employ designs involving interviews, semi-structured interviews or self-report checklists to investigate an individual's way of coping. For example, in open-ended interviews where a person is asked how he or she coped with a stressor, problems arise because each person may interpret the question differently (Horowitz & Wilner, 1980). This diversity complicates any form of quantitative or qualitative analysis.

Structured interviews are an alternative to the open-ended interview. Preset questions ask about an individual's feelings, thoughts and approach to dealing with a previously encountered problematic situation (Cohen, 1987). With the structured interview format it is possible to establish validity and inter-rater reliability, although it is time-consuming. When children are involved, it is sometimes difficult to hold their attention throughout an interview.

Self-report checklists on the other hand are quick, easy to use, can yield important information and are relatively objective. The data are reliable and suited to quantitative analysis and comparable across and between individuals. However, interesting and vital information may be lost along the way.

The process of coping is evaluated through the kinds and number of coping strategies used. To assess coping strategies used by children self-report questionnaires were devised. When developing *Kidcope* for Younger Children (Spirito, Stark, Grace & Stamoulis, 1991) and *Kidcope* for Older Children (Spirito, Stark & Williams, 1988) *the Ways of Coping Scale* was used as the fundamental starting point.

1.3.1 For adults: the Ways of Coping Scale

The self-report checklist developed by Folkman and Lazarus (1980) was designed for adults. *The Ways of Coping Scale* was originally used with 68 items and these items describe a broad range of cognitive and behavioural coping strategies. Two notable properties reflect the transactional model discussed earlier. First, the questionnaire is intended to be used as a measure across varying situations and time. Secondly, the person reports both cognitive and behavioural strategies in terms of a specific stressful situation that has recently occurred. The 68 items were answered as *used* or *not used* when dealing with the problem and resulted in nominal data.

Lazarus and Folkman (1984) subsequently revised the scale and changed it to a 4 point Likert-type format ranging from *not used, used somewhat, used quite a bit* to *used a great* deal, resulting in ordinal data. Here the individual indicates to what extent he or she used each strategy while coping with a specific situation described earlier. A psychometric instrument measuring responses which result in ordinal data is thought to be preferable to the responses which result in nominal data. This preference stems from a less restricted measurement scale and the wider range of statistical tests available for ordinal data.

However, if researchers focus on the coping model put forward by Lazarus and Folkman, it is questionable whether a 4 point scale is 'an improvement' on the original version which presented the simple choice of *used* or *not used* to the

items on the Ways of Coping Scale. As subjects are asked to respond to a *specific* stressful situation when completing the scale and not what usually happens, this hardly seems sensible.

The revised Ways of Coping Scale is made up of 67 items, for example: Q8 'I talked to someone to find out more about the situation', Q13 'I went on as if nothing had happened', Q38 'I rediscovered what is important in life' and Q54 'I tried to keep my feeling from interfering with other things too much'. This questionnaire is complex and lengthy with a high demand on participants' literacy skills. The modified version of the Ways of Coping has been used with adults in several different studies (Baum, Fleming & Singer, 1983; McCrae, 1984; Parker, 1984, and Nakell, 1985; all in Cohen 1987). However, there does not seem to be a standard way to score this instrument. Both general and more in-depth methods of analysis have been employed. Some researchers used only a few broad categories, for example emotion focused coping versus problem focused coping, to give an indication or a general outline of the coping process. Others used a large number of items, often submitting them to factor analysis.

Cohen (1987) reports four different studies based on the Ways of Coping Scale. The four data sets were factor analysed. From these data four groupings of different factors were found. Folkman *et al.* (1986), for example, found eight factors (confrontive coping; distancing; self-control; seeking social support; accepting responsibility; escape/avoidance; planful problem-solving and positive appraisal) and of these eight factors only five coincided with the ones identified by the other researchers. Unique factors were also found in each grouping. Bearing in mind that all four studies were based on the same instrument, it is the method of administration, the participants themselves and the analyses that should be looked at in detail (beyond the scope of this write-up). Thus widely differing subject groups or the quality of the instrument itself may partly be the cause of inconsistencies.

Furthermore, the inconsistencies can also be related to two important features of the coping definition stated by Lazarus and Folkman (1984). First, coping is seen to be *process oriented*; that is to say coping refers to what each person actually thinks or does and not to what the person is 'expected' to do. And secondly, it refers to what a person thinks and does within a *specific context*, a specific stressful situation, and not to general stressful conditions. It might therefore be said that the inconsistencies between factors found in the four studies are influenced by the subject population as well as by differences in the stressful situations studied; for example, students at university, patients in hospital or middle-aged adults in their place of work.

1.3.2 For children: the Kidcope Checklist

The Kidcope Checklist, one of the instruments used in this thesis is brief and easy to administer yet is a complex instrument which taps numerous aspects of coping. The validity and reliability of Kidcope are discussed in Chapter 3 and Section 6.6.

The Kidcope Checklist requires children to think of a *recent problem* and to rate their *distress* response to it. They then complete the questionnaire with regard to that problem. The child indicates whether he or she had used one or more of the ten cognitive and behavioural coping strategies (*Distraction, Social Withdrawal, Cognitive Restructuring, Self-criticism, Blaming Others, Problem Solving, Emotion Regulation, Wishful Thinking, Social Support* and *Resignation*) and rates how *helpful* those strategies were when dealing with the problem. Kidcope can be administered more than once during an interview or repeated over time. The methodology and procedure are described in Chapter 3 and Section 4.1.

Lazarus (1981) claims that it is possible to carry out objective research on a dynamic process which changes over time and across situations. He, in collaboration with other researchers, has explored ways of studying the process of coping in adult

populations. He suggests that when studying an individual over time and across stressful encounters, it is possible to assess the degree of stability and change of given coping patterns. The settings and types of encounters that influence these patterns can be examined. According to him research of this kind is best generated within the transactional model. Developing ways of measuring coping may depend on the processes and changes that occur from moment to moment within the same encounter, or across encounters. In this thesis the validity of this claim will be considered in the context of ill children's way of coping.

1.4 Assessing coping in ill children

It is important to understand what it is that children with a seriously illness find stressful. At the same time the coping mechanisms they use need to be identified. Even though researchers and clinicians agree that coping forms an important part of the understanding of adaptation to stressors, including stressors associated with serious illness, the sparse empirical literature on young patients highlights the gap between theory and research. According to Spirito, Stark and Knapp (1992) it is not only research that lags behind, but assessment of coping in clinical practice is also limited. As coping is said to change across person, time and stressor, the study of coping is naturally complex. These complexities are magnified in children's coping. A child's ability to assess a situation as stressful and to recognise the available coping resources depend partly on the child's developmental level.

The issues which are addressed in this chapter are based on the notion of coping as a specific process in a transitory situation. While this model has been widely accepted (Compas, Worsham & Ey, 1992) other theorists hypothesise that individual coping styles are relatively consistent across situations and might be thought of as traits.

However, these so called trait theories of coping have been unable to predict how children will cope in different contexts (Lazarus & Folkman, 1984).

Although a person may characteristically respond to similar stressors in a familiar way, consistency across different stressors is not to be expected, even with the same individual (Peterson, 1989). For example, how a young patient with an aversion to blood tests copes while anticipating a blood test may be very different from the coping method used while holding out their arm and cooperating with the doctor as the needle goes in.

The two approaches to coping measurement, those of coping style and coping process, ask different questions and provide different answers. Coping style focuses on individual differences, while the coping process emphasises the temporal and contextual influences on coping. Thus, when looking for a predictable pattern of coping it is not only the individual differences of the children that need to be taken into account (for example, sex, age, time since diagnosis) but also the types of stressor reported by the children within different contexts (for example, a fight with a friend at school or missing a friend while staying in hospital). In the past there was a lack of conformity in the methods used to collect and analyse data. The different ways in which coping was evaluated limit the extent to which comparisons can be made across studies.

1.4.1 Assessing coping: a variety of methods

In 1990 three articles on the topic of children's coping during a medical procedure were published simultaneously. The research was done by Richie, Caty, Ellerton and Arklie, and Peterson, Harbeck, Chaney, Farmer and Thomas who based their work on the coping paradigm of the transactional model discussed in Section 1.2, and by Lumley, Ables, Melamed, Pistone and Johnson, who described the outcome responses

of children's contact with medical stressors, relating those outcomes to the children's temperament and to their mother's behaviour before the venipuncture and anaesthesia induction.

Peterson *et al.* and Lumely *et al.* attempted to measure child based factors predicting different responses to stress while Richie *et al.* targeted the degrees of experience with stressful medical procedures (a fingerprick procedure) as a predictor. The studies by Lumley *et al.* and Richie *et al.* will be reported in more detail in Section 1.5.2. The work by Peterson *et al.*, discussed below, considered different phases of children's transaction with the stressor. All three studies struggle with the challenge of devising measures that take account of critical aspects of the child (such as experience, temperament, or typical mode of coping) and the environment (such as procedure type or parental influences) which influence coping.

By attempting to establish a conceptual base for children's coping with medical procedures, Peterson *et al.* (1990) started by considering some of the literature on adults ways of coping with major life events and daily hassles (Folkman & Lazarus, 1980; Moos & Billings, 1982; Stone & Neale; 1984). Peterson *et al.* argued for and worked on a developmentally specific model, using some of the essential components from adult coping models, for example the transactional model of coping.

In their study Peterson *et al.* (1990) recorded three aspects of illness reported by 60 healthy children. First, the children took part in one-to-one interviews. They were asked to discuss their typical responses when faced with a medical procedure experienced in the past. Second, split into pairs they role played having an injection themselves and helping a friend who was undergoing a blood test. And finally, the interviewer performed the role of a doctor asking the children to pretend to be ill. Results were reported in terms of Appraisal coping for Self or Other.

It was found that the seeking of information for others was used significantly more often than information seeking for themselves.

Peterson *et al.* made a start with the conceptual base of children's ways of coping by drawing on adult literature. They attempted to construct a child-specific model to describe and predict coping with an invasive medical procedure, arguing for the need to consider the component stages of coping. They urge consideration of developmental levels when assessing children's coping. Unfortunately the empirical work presented in their paper, which was based on healthy children with little if any experience of a consulting room or a hospital setting, is weak and yields few results to build on.

Peterson (1989a) summarised a set of eight studies examining children's coping in response to various stressful medical procedures to illustrate research trends in coping. Only one dimension of coping was considered, which resulted in the suggestion that children used either information-seeking or information-avoiding strategies. Information-avoidant coping was defined in a variety of ways: the tendency of a child to avoid or deny stress by selecting toys not relevant to the medical encounter, not asking questions about the medical procedure, and by looking away during the preparation of the medical procedure. Information-seeking coping was conceptualized as a willingness to encounter information, such as playing with medically relevant toys, watching the preparation with interest, or asking questions related to the medical procedure.

In her comprehensive review of the research on children's way of coping with stressful medical events, Peterson concludes that despite different methodologies and terminologies a range of coping from passive/avoidant to active information seeking was the one dimension consistently identified in all studies. Work by Hubert, Jay, Saltoun and Hayes (1988) and Phipps, Fairclough and Mulhern (1995) describes

different ways of assessing coping behaviour (active or avoidant) by children with cancer and is reported in Section 1.5.2.

Eve Band (1990) used a structured interview format to explore potential differences in coping by diabetic children. Sixty four children aged 7 to 17 were interviewed. They were asked to rate their perceptions of control and coping competence and to describe their coping efforts in response to various stressful aspects of their illness and its treatment. The children's descriptions of coping behaviour were coded along a single dimension of primary control, defined as 'trying to directly change stressful conditions' and secondary control, defined as 'trying to adjust to circumstances as they are'. Sex and age of the children were also considered.

The direction of the group-means indicated greater secondary control coping, which requires more abstract thinking among older children than among the younger children. This result supports an earlier finding by Band and Weisz (1988) where an age effect in healthy children's self-report coping was established. Younger children used more primary than secondary coping, indicating they preferred to perform an action to change the environment rather than use cognitive abstraction to fit into existing stressful situations. Band found no differences between boys and girls with diabetes and their use of primary or secondary control coping. She concluded her paper by reminding the reader that the challenge remains to explore more specific interactions between coping strategies and various stressors.

Bull and Drotar (1991) addressed the question of whether or not children with cancer use similar coping strategies to manage different stressors; especially cancer versus non-cancer related stressors. Studies by healthy children and adolescents suggest that they use more consistent coping strategies than adults to deal with a range of academic, family, social and health-related stressors (Compas, Forsythe & Wagner, 1988; Folkman & Lazarus, 1986). The Children's Stress Inventory (CSI, Wertlieb

et al., 1987) was used to assess the children's perceptions of their coping strategies in response to general life stressors and a structured interview was carried out to assess children's reactions to specific cancer-related stressors.

Thirty nine children with cancer aged 7 to 17 completed the two coping measures, the CSI and the structured interview. Significant differences were found in the way the children coped with stressors related to school or siblings, and treatment or a handicap resulting from the illness. In their study, Bull and Drotar measured coping across the self-selected stressors with different instruments, one of which assessed the everyday stressors and the other the illness related stressors. The methodology applied makes comparisons between the two situations and the coping strategies used subject to doubt.

It is essential that stressors, coping processes and coping outcomes are clearly conceptualized before introducing further complexities in this area. In order to achieve consistency across studies, there must be a consensus about *what* is being measured and *how* it is measured. The development of the Kidcope Checklist (Spirito *et al.*, 1988, 1991; Pretzlik & Hindley, 1993), may go some way towards overcoming this problem.

1.4.2 Assessing coping: the Kidcope Checklist

As part of a clinical interview Spirito *et al.* (1988) asked 38 paediatric patients with a variety of illnesses and an age range of 10 to 18 years to complete the recently developed Kidcope Checklist for Older Children in response to a personal *illness related* stressor. The patients reported the number of strategies used and how often they used them; assessment of the content of the scenarios, the distress element and the helpfulness part of Kidcope were omitted. Although the Kidcope Checklist is based on the transactional model of coping, the frequency of the coping strategies

was reported on a 4 point Likert-type scale (*not at all, sometimes, a lot,* and *almost all the time*) and not simply *yes* or *no.* By using the Likert-type scale the idea of dealing with 'a specific stressor in a specific situation', which forms part of the Lazarus and Folkman theory, was ignored. As Kidcope was completed within one context only (illness related), comparisons as far as stability or instability of coping strategies across situations was concerned could not be evaluated.

These 38 children were compared to a sub-sample of 68 healthy adolescents who reported coping strategies they had used for a *school related* stressor. The frequencies are reported in percentages and use the terms '*a lot of the time*' and '*most of the time*' from the 4 point Likert-type scale. *Distraction* and *Social Withdrawal* were used significantly more often by the patient group reporting an illness related problem than by the healthy children reporting a school related problem. However, *Self-criticism* was used more by the comparison group (healthy adolescents) than by the paediatric patients.

Asking different groups of children to report on different problems and then comparing how often they used coping strategies seems an unsatisfactory way of looking at the process of coping. Spirito *et al.* collected the data in the form of clinical interviews, and this may have contributed to the lack of scientific rigour. It is clear that a tighter design and a more systematic approach to data analysis was needed.

In 1991 Spirito *et al.* published the first paper using the Kidcope Checklist for Younger Children. The Kidcope Checklist for Older children was changed by simplifying the language and increasing the 11 coping items to 15 coping items. The 15 coping items are broken down into ten coping strategies, the same as for Kidcope for Older Children. A simple answer of *yes I did* or *no I didn't* replaced the earlier Likert-type scale indicating whether a strategy had been used or not (details are reported in Chapter 3). Administration of the checklist was carried out by teachers

with groups of children in the classroom. In all 676 children from 9 to 14 years were asked to describe a common or everyday problem.

The children's scenarios were categorised and four typical stressors emerged. They were related to the children's parents or siblings, and to school or their friends. The type of stressor reported by boys and girls, and whether they were older or younger, did not differ significantly. After looking at the content of the stressors (scenarios), the way of coping with these stressors was considered. The kinds of coping strategies used differed by age and type of stressor. Younger children (9-11 years) reported to have used Distraction, Problem Solving and Emotion Regulation more than the older children, and older children (11-14 years) used Blaming Others more than the younger group. Significant differences were found between some of the coping strategies and the type of stressor used; Cognitive Restructuring and Self-criticism were used more for dealing with school related stressors than sibling related stressors and Blaming Others more for friend related stressors than either sibling or school related stressors.

The overall number of coping strategies reported to have been used by younger children was higher than those used by older children. This finding and the results by Curry and Russ (1985), Wertlieb, Weigel and Feldstein (1987) and Pretzlik and Hindley (1993) suggest that younger children (9-11 years) use a greater number and variety of coping strategies than older children or children younger still.

Although Spirito and his colleagues (1991) asked the children to report on the perceived helpfulness of each coping strategy, the results of this data were not published.

Before relating the way children cope to *different* contexts, it would be sensible to analyse and categorise the content of scenarios described by the children in *specific*

contexts. Given such a large sample of 676 children the number and kinds of coping strategies used for the type of stressor (parent, siblings, school or friends) within the common context could and should have been compared.

Given that coping is an interactive process as portrayed by the transactional model, it may be that it is affected both by individual differences and by the context. However, if coping is more strongly affected by individual differences than by contexts, then age and sex effects should be relatively stable across different contexts.

One hundred and seventy seven chronically ill children took part in a recently published study by Spirito, Stark, Gil and Tyc (1995). The children suffered from sickle cell disease n=66, diabetes n=41, cancer n=23, migraine n=15 and others n=32. They were between 7 and 18 years of age. The Kidcope Checklists for Younger and for Older Children were completed across two contexts, a common or everyday problem and a chronic illness related problem.

In this latest study by Spirito *et al.* several analyses were undertaken to see if coping is stable and affected by individual differences or whether it is affected by the context in which the problems are reported. First, the age and sex of the children were considered, and whether or not they influenced the way the patients coped within and across the two contexts - a common problem and a chronic illness related problem. Results for age suggest more situational variation in coping; out of the ten coping strategies used for each of the two problems only one, *Resignation*, was used significantly more by the older children than by the younger children. *Blaming Others* was also used more by the older children when describing a chronic illness related problem, but not when describing a common problem.

For the chronic illness related problem, boys reported using *Cognitive Restructuring* and *Self-criticism* more than girls, whereas girls reported using *Emotional Regulation*

and *Social Support* more than boys. However, when referring back to a common problem no differences were found between boys and girls and the type and number of coping strategies they used. These results show a degree of consistency within but not across contexts.

Analyses were also carried out comparing coping strategies used by the same child for different problems. Kappa coefficients were calculated and moderate agreement was found. This result confirmed that the children tended to use the same coping strategy for the two specific scenarios they had reported across two contexts (common and illness related) and suggests that the individual child used similar coping strategies to cope with different problems. Yet, these results indicating consistency across contexts deviate from the results reported on the same group of children in respect of age and sex mentioned above. There some stability was found within but not across contexts. Moreover the reported stability across the two contexts also deviates from the definition by Lazarus and Folkman. Their transactional model assumes that an individual will cope with similar situations in the same manner, depending on the degree to which the same discriminative stimuli are presented across situations. Lazarus and Folkman maintain the notion that what a person thinks and does is influenced more by the context in which the problem occurs than by the person's individual differences or traits.

The role of the stressor that elicits coping is an important conceptual unit. It might therefore be said that a stressor requires a variety of different responses dependent on context. Thus, the way in which a child copes with a relationship problem bears little resemblance to the way in which the same child would cope with physical pain. However, if the specificity argument is carried to its rational extreme there would be little point in studying coping. In such a case each reaction to a stressor would be unique and unpredictable and would be uninfluenced by previous coping attempts and past experience with other stressors. Logic dictates that this cannot be and that

experience gained should assist a child to cope with a similar stressor to the one which provided that experience in the first place. Thus, a child will cope with similar stressors or situations in similar ways. So far no empirical data has been published to support this reasoning.

It is encouraging to note that the three studies discussed in this section used similar methods to assess coping strategies, thereby making comparisons possible. Spirito *et al.* (1988, 1991, 1995) looked for consistency and similarities between children and/or stressors. The links reported to have been found are weak and somewhat inconsistent, as is the methodology. Not all results of data reported to have been collected were published. For example, what throughout this thesis is called self-reported distress and what Spirito *et al.* call appraisal, and what here is called perceived helpfulness and Spirito *et al.* call efficacy, were mentioned but not addressed.

Researchers should start with a solid and simple base of enquiry, then expand gradually. The first task in this thesis will be to establish reliability and validity of the Kidcope Checklist. The second task will be to verify some of Lazarus and Folkman's theoretical claims. Only then can a more complex assessment of children's coping mechanisms be addressed.

1.5 Assessing distress in ill children

In his publication, *Emotion and Adaptation*, Lazarus (1991) refers to distress not as a basic emotion but as a reaction to stress with emotional overtones and diffused meaning,

> 'apt to be used in the context of stress rather than for identifying a particular emotion with a particular content' (p.83),
>
> Lazarus adds that 'we cannot understand the emotional life solely from the stand point of the person or the environment as separate units' (p.89).

It can therefore be said that the relationship between distress and coping is multy-directional with each affecting the other.

In their 1988 paper, Folkman and Lazarus state that the appraisal process (Section 1.2.2.2) generates emotion. The appraisal and its underlying distress influence coping processes, and the coping processes in turn change the person-environment relationship. The transformed or modified person-environment relationship is reappraised and will then, according to Folkman and Lazarus, lead to further change in emotional quality and intensity. Looked at in this way, coping is a part-mediator to emotional responses.

The difference between *moderator* and *mediator* variables is conceptually and methodologically important (Baron & Kenny, 1986). Moderators are existing conditions such as sex, age or personality traits which interact with other conditions in producing the outcome. A mediating variable is generated during the encounter and changes the relationship between the existing and the outcome variable. As a mediator, therefore, coping transforms the original appraisal and its underlying distress.

In this thesis the term 'emotion' is limited to *distress*, that is to say, a reaction to a stressful situation both observed and self- reported.

1.5.1 Assessing self-reported distress: the Kidcope Checklist

In their 1991 study Spirito *et al.* reported results from groups of school children who completed two of the three original distress elements (feeling nervous and feeling sad) of the Kidcope Checklist. Two groups were formed: the *non-distress* group rated their level of nervousness and sadness as 0 (not at all), 1 (a little) or 2 (somewhat), while the *distress* group included children who reported their specific stressor making them feel nervous and sad as 3 (pretty much) and 4 (very much). No significant difference was found between distress, type of problem and sex, although children who reported being distressed by a problem with their parents or friends were more likely to use Emotional Regulation to help them cope than children from the non-distress group.

Fifty four chronically ill children and 71 acutely ill or injured children (7-17 years) completed Kidcope and the three original distress elements (Spirito, Stark & Tyc, 1994). In this study the ratings of the 5 point Likert-type scale were again dichotomized as *not having occurred* (0) or as *having occurred* (1,2,3,4). No significant differences were found between sadness or anger across different problems (illness related, pain related or hospital related). It was found, however, that more children felt nervous when talking about a pain than when they talked about a hospital related problem. Children who were distressed used Problem Solving, Social Support and Wishful Thinking more often than children in the 'not having occurred' group.

It should be noted that the same instrument was used in the two studies. However, there was no consistency between the methodology used in the 1995 study and that used in the 1991 study to dichotomize the data.

In 1993, for the first time, Pretzlik and Hindley measured and reported both the self-reported distress and helpfulness scores. During one-to-one interviews 32 healthy

children were asked to rate their feelings about two personal stressors they had described in the common and in the illness related context. In this study, the Kidcope distress score was made up of the three distress elements: feeling *nervous* or *anxious*; *sad* or *unhappy*; *cross* or *angry* (Section 3.1.2). The data has a possible range of 1 to 5 for each of the three distress elements and 1 to 3 for the helpfulness part. Results show younger children (5-7 years old) who had higher distress scores used more coping strategies than children with lower distress scores. Older children (8-10 years old), who felt *angry* about their problem, perceived the coping strategies they used as more helpful, while younger children, who reported feeling *unhappy* about their problem, perceived the strategies they used as less helpful.

Furthermore, Pretzlik and Hindley found that children's distress scores were significantly related to three coping strategies: *Distraction, Emotion Regulation* and *Resignation.* The more the children used *Distraction* the less overall distress they reported. The less they used *Emotion Regulation* and *Resignation*, the more distress they felt.

The area of self-reported distress deserves further exploration. All three studies, employed the Kidcope Checklist yet each of them used a different method to analyse the data, thus making comparability between them difficult. So far no reliability or validity data of the distress elements of Kidcope has been published; yet assessment of children's feelings of distress related to their chosen stressor is of interest. To learn more about children's distress and to be able to compare patient groups and contexts, it will be necessary for this part of Kidcope to be set on a more solid footing.

1.5.2 Assessing coping and distress behaviour: a variety of methods

Peterson and Toler (1986) examined children's information-seeking behaviour in relation to several measures including a modified version of the Coping Strategies

Interview (Siegel, 1981, cited in Peterson & Toler, 1986). Fifty nine surgery patients aged 5 to 12 years took part. The reported results were based on data from multiple raters and situations and supported validity of an information-seeking construct in children. These findings were indicative of an inverse relationship between information-seeking type of coping and distress behaviour related to the medical procedure.

Both Hubert *et al.* (1988) and Phipps *et al.* (1995) in their recently published study looked at children's coping behaviour in the medical setting. In each case a newly developed instrument was used. Hubert *et al.* used direct observation (The Behavioural Approach-Avoid and Distress Scale, BAADS) and Phipps *et al.* asked the children how they behaved (The Children's Behavioural Style Scale, CBSS). The coping behaviours were measured in one dimension only - in terms of avoidant or active coping.

Hubert *et al.* observed 43 children aged 3 to 11 before they underwent their first diagnostic BMA for leukaemia; that is to say during their preparation for the procedure. The BAADS consists of two subscales, one measuring approach-avoidance behaviour and the other measuring distress behaviour. On the approach-avoidance subscale high *approach* behaviour is defined as: looks, touches, questions, or initiates involvement. High *avoidance* behaviour is defined as: turns away, tries to escape or change the situation. On the distress subscale ratings ranged from no distress, calm appearance, no crying to extreme distress, agitation, screaming, to extreme muscle tension. Behaviours on both scales have a possible range of 1 to 5.

When approach-avoidance behaviour was displayed, no difference was found between older and younger children or between boys and girls. Children's self-reported ratings of fear obtained by using the Faces Scale (Katz, 1979, cited in Hubert *et al.*, 1988), and collected following the preparation and before the BMA were significantly

associated with the distress scores, but not with the approach-avoidance scores. The BAADS approach-avoidance scores were negatively related to distress behaviour during the medical procedure and during earlier observation.

Phipps *et al.* (1995) found children with cancer (n=66) used avoidant coping behaviour more than healthy children (n=414). Within the group of children with cancer a positive association was found between those who were avoidant and the time since their diagnoses. This result suggests that the increased avoidance in children with cancer is a reactive occurrence - and may partly be due to the likelihood of the illness and treatment continuing for some time. Possibly the children feel better not knowing too much.

In an early study Hyson (1983) used systematic observational methods to examine what she called the emotional responses and coping behaviour of 48 children (6-60 months). The children underwent a checkup in a paediatrician's consulting room. Hyson's study focused on two kinds of response: facial expressions of emotion (Anger or Fear) and overt clear behaviour (Information Seeking or Autonomy). The complex set of behaviours were observed before the doctor's entrance, during the physical examination, and after the examination. They were coded at 30 second intervals. Results show the effect of age, when younger children displayed more negative emotions than older children, and of timing, when more negative emotion was shown during the physical examination than before or after the examination. These behaviours are similar to, yet more intricate than, the distress behaviours reported in later work by Jay and Elliott (1986).

Ritchie *et al.* (1990) extended Hyson's study. They developed an observation instrument that describes what is here called verbal and nonverbal *coping behaviour*. Seventy four children (24-67 months) were observed during a fingerprick procedure. The children were divided into three groups with little, moderate or extensive

experience with hospitalization. About half the children had a parent present during the procedure, but the parental presence was not controlled for. The Children's Coping Strategies Checklist (CCSC, Ritchie, Caty & Ellerton, 1988) was applied. Age was found to have an effect on some of the coping behaviours, it predicted Information Seeking/Participative behaviours, but did not effect other types of coping. No differences were found between the three illness groups in respect of the total number of coping behaviours or the type of behaviours the children displayed. Procedure length, however, was a significant predictor of the total number of coping behaviours and Information Seeking/Participative behaviours. The longer a fingerprick took to extract the right amount of blood the more coping behaviour was observed. The procedure length ranged from 2 to 9 minutes.

As in Richie *et al.*'s study, LeBaron and Zeltzer (1984) found that younger children showed greater evidence of behavioural distress than older children - but only during the actual medical procedure. Sixty seven children aged 6 to 18 were observed during a bone marrow aspiration (BMA). The observation instrument was developed for this study and is based on the Katz, Kellerman and Siegel (1980) structured observation checklist (Section 1.5.3). The overall goal of LeBaron and Zeltzer's study was to compare the usefulness of self-reports, observations, and a behavioural checklist for assessing acute pain and anxiety in children with cancer. They suggested that before behaviour interventions for medical procedures can be established, clinical research on pain and anxiety must rely on or refer to some form of assessment of distress and should therefore incorporate both self-reported and observed data.

1.5.3. Observing distress during a medical procedure: the Observation Scale of Behaviour Distress

Only by understanding how children typically deal with stressful situations can an intervention be designed to enhance rather than conflict with their reactions. Medical

procedures are encountered by a large number of children and are universally regarded as stressful situations making them an ideal 'laboratory' to study children's responses to stress. Needle-based procedures have, despite their relatively short duration, been rated as amongst the most stressful medical procedures for children.

One objective way to assess children's level of distress is to observe their behaviour during a painful or uncomfortable medical procedure. Paediatric patient's distress can be assessed by using a structured observation method in the form of the Observation Scale of Behaviour Distress (OSBD). The total distress behaviour is made up of eight categories (*Information Seeking, Cry, Scream, Restraint, Verbal Resistance, Emotional Support, Verbal Pain* and *Flail*). The same instrument was used in the studies discussed in this section, allowing some degree of comparison between research related to children undergoing a medical procedure. The OSBD was first developed by Katz *et al.* (1980) and next revised by Jay and Elliot (1981, 1986). It is designed to assess children in a medical setting and is a valid, reliable instrument used extensively, but mainly in the USA. Validity and reliability is discussed in Chapter 6, Sections 6.1.1 and 6.1.2.

Bone marrow aspirations in 115 children with cancer, 108 of whom suffered from leukaemia, and who had an age range from 8 months to 18 years, were observed and had their anxiety responses measured. Distress behaviour in this group of children was widespread, and Katz *et al.* (1980) noted the need for intervention. It was found that age influenced children's behaviour. Younger children showed consistently higher levels of distress behaviour than older children; due to the wide age range a not unexpected result. Qualitative differences were also found in the way their distress was expressed. Younger children showed more body movement and cried more than the older group. It should, however, be remembered that medical practice for BMA has changed and improved considerably during the last few years.

Katz and her colleagues also found that children who asked more questions about the BMA exhibited less distress behaviour, indicating that actively engaged children coped better. The time since the children were first diagnosed to have cancer ranged from 1 to 76 months. These children's previous experience of this medical procedure was not found to affect their distress behaviour, and both boys and girls showed similar levels of distress throughout the medical procedure.

Jay, Ozolins, Elliott and Caldwell (1983) observed 42 cancer patients within an age band of 2 to 20 years during a BMA. They used an observation schedule based on the one developed by Katz *et al.* (1980). The results from the OSBD in this study also show a marked age difference; younger children were visibly more distressed than older children. However, the level of behavioural distress was found to decrease and level off when children reached the age of 6 or 7 years.

Two measures were used to help discover if and how experience might influence patients' distress levels, i.e. the number of previous BMAs a child had experienced and the number of months since the child was first diagnosed with the illness. Negative yet significant correlations between the OSBD distress scores and the number of previous BMAs, and the OSBD distress scores and the number of months since the illness was first diagnosed imply that the majority of the 42 children adjusted to the medical procedure.

Finally children's temperament and their mothers' behaviour (presence or absence) before a medical procedure were considered by Lumley *et al.* (1990). The children's distress behaviour was observed, again using the OSBD. Results suggested that the mothers' behaviour was related to the children's responses to the anaesthesia induction. They also found that the children's temperamental characteristics of adaptability to change and Approaching versus Withdrawing were related to the children's coping with the induction. Their temperament and the mother's behaviour

interaction predicted coping behaviour. These relationships were independent of the child's age, and previous experience with surgery.

Lumley and her colleagues' work assessed children's reactions to a medical stressor. These reactions are children's distress behaviours and are classed as outcomes of coping. Lumley *et al.* argue that they examined children's temperament and maternal behaviour in an attempt to improve understanding of the coping process by which coping outcome is influenced. They conclude that these moderating variables influence coping outcomes, and affect a child's coping strategies. Yet, they did not assess the coping strategies used by the children who took part in their study.

1.6 A final comment

An interactionist model assumes, by definition, that a child's 'success' or 'failure' to cope with a serious illness is dependent upon a multiplicity of factors. Many of the potential influences will be looked at in Chapter 2. The conceptualisation of children's coping should include moderator variables, for instance characteristics such as self-esteem, and parental presence or absence during a medical procedure and the influence of parental coping with their child's illness. Such variables, without doubt, have influence on the consistency or variability of children's coping across and/or within stressors.

Having looked at the concept of coping and related empirical work, Chapter 2 will focus on factors, both psychological and social, which it is believed assist ill children in the way they cope.

CHAPTER TWO
PSYCHOLOGICAL AND SOCIAL FACTORS INFLUENCING COPING IN ILL CHILDREN

In this second part of the literature review an attempt is made to provide theories and findings related to psychological and social factors believed to support and/or influence ill children's coping. This chapter is particularly relevant to research questions asked in later chapters (Chapters 7, 8, and 9) and is loosely divided into four sections. In the first section reported work related to children's individual differences, including their perception of competence and self-worth, will be considered and where possible will be related to findings of children's coping and distress with their illness and medical treatment (Sections 2.1). In the second section a brief yet complex discussion of literature related to children coping with their illness and familial factors will be looked at. Theories and empirical data are presented to describe parental coping (Section 2.2) and family models and the social environment of the family (Section 2.3). In the final section the literature which refers to psychological and social factors is related to the thesis (Section 2.4).

2.1 Individual differences and coping

Children's self-esteem, their age, sex and experience with their illness constitute what in this thesis are called individual differences. It is these individual differences and their possible influence on children's coping with an illness that are considered in this section.

2.1.1 Age, sex and experience and coping

The question as to whether or not children's age, sex or experience with a medical procedure or an illness in general affects their coping has already been addressed extensively in the previous chapter.

In a recent study by Sylva, Stein and Bonn (1993b) 81 children aged from 3 to 6 years were observed in hospital during admission for either acute asthma or for ophthalmic surgery. The children were observed in three situations - undergoing a medical procedure, during a meal and while playing. Their coping behaviour was measured using a variant of the OSBD (Katz *et al.* 1980) and it was found that age was significantly related to the assessed coping behaviour. Younger children showed more dependency behaviours (physical contact, receiving cuddles, request attention and are demanding) than older children. No significant differences were found between the boys and the girls and their coping behaviour.

In their study Altshuler and Ruble (1989) interviewed 24 school children at three age levels between 5 and 12 years. Scenarios describing 'having to wait in uncontrollable situations' were presented to the children. Older children reported using cognitive distraction coping strategies significantly more often than younger children. However, all the children, irrespective of age, reported having used behavioural distraction more frequently than cognitive distraction.

An open-ended interview format, where subjects described both an interpersonal and an academic problem, was used to assess 130 healthy children's (10-14 years) coping with their personal stressor (Compas, Malcarne & Fondacaro, 1988). Two coping categories were established, emotion focused and problem focused. It was found that problem and emotion focused coping was used by older and younger children in response to both academic and interpersonal stressors, and that with the one

exception no significant differences were found between boys and girls in the generation and use of coping strategies. The exception was that in response to academic events girls used more emotion focused coping strategies than boys.

A representative number of studies were reported in both Chapter 1 and in this section. They related to children's *age* (e.g. Spirito *et al.*, 1991; Pretzlik & Hindley, 1993; Katz *et al.*, 1980) and *sex* (e.g. Spirito *et al.*, 1995; Hyson, 1983) as well as to their *experience* with their illness (e.g. Elliott *et al.*, 1987; Richie *et al.*, 1990). The resulting picture is not altogether clear. Although coping should be thought of as a developmental process with obvious age related shifts (Peterson, 1989b), research findings do not consistently support this notion.

2.1.2 Self-esteem and coping: the Self-Perception Profile for Children

Self-esteem is viewed as a coping resource (Moos, 1974; cited in Moos & Billings, 1982). Individuals with higher self-esteem are thought to be more active and persistent in their efforts to handle stressful situations than those with lower self-esteem who are less active and tend to avoid such situations. Several theorists have defined the competent self as an individual who combines a favourable self-attitude, namely self-esteem, and an active approach to coping with their environment (Moos & Billings, 1982).

When Susan Harter developed her original model of children's self-esteem she turned to two scholars of the self, James (1892) and Cooley (1902), for theoretical guidance. Both James and Cooley stressed that individuals possess a global concept of self over and above more specific self-evaluations. For James global self-esteem was the ratio of success to aspiration. According to this notion individuals do not scrutinize their attributes or their every action, rather they focus on their ability in areas of importance to them, i.e. in those areas where they aspire to succeed. Thus, if the

individuals perceive themselves as competent in areas were they aspire to excel, they will have high self-esteem. On the other hand the failure of individuals to achieve the goals and ideals they have set themselves, will be followed by a feeling of low self-esteem.

In contrast to James, who focused mainly on the individual's cognitive evaluation of adequacy, Cooley theorised that the origins of self-esteem were first and foremost social in nature. Cooley adopted a mirror metaphor in describing his concept of the 'looking glass self' and he views the reflected judgements of others as being important in how the individual sees him or herself. Mead (1934) elaborated on this theme in his concept of the generalized other person, which represented the pooled or collective judgment of the significant others in an individual's life. It is said that when others hold the self in high regard an individual's sense of self-esteem will be high. Yet, if others have little regard for the self, these negative opinions will be reflected in low self-esteem.

Harter's model of self-evaluation in children lends itself to James' analysis of 'the ratio of success to aspiration'. It was found that from about eight years on children develop domain-specific evaluations of their competence and adequacy in addition to an increased global concept of their worth as an individual (Harter, 1982). The domains which form part of the Self-Perception Profile for Children (SPPC, Harter, 1985) are *Scholastic Competence, Athletic Competence, Social Acceptance, Physical Acceptance* and *Behavioural Conduct.* The results from the SPPC self-report questionnaire establish a profile of self-concept scores in the specific domains, as well as a separate index of the child's sense of *Global Self-worth.* Details about this self-report instrument including validity and reliability, are reported in Chapter 7.

Self-esteem or self-worth within the framework used by Harter (1991) has been conceptualised as the level of global regard that an individual has for the self as a

person. For example, the importance to the child's self-worth of other people's judgement (Cooley, 1902) is reflected by the fact that Physical Appearance followed by Social Acceptance has been found to be the most important predictor of Self-worth for children 8 to 15 years of age (Harter, 1990). Harter found that the link between Physical Appearance and Global Self-worth continues throughout the life span of an individual.

The SPPC was both designed for and had its reliability and validity established with healthy school children. Nevertheless, according to Eiser (1990) families and children coping with illness should be seen as ordinary people in extraordinary circumstances. If this logic is followed through, it would be reasonable to use the SPPC with physically ill children. To date, with just a very few exceptions such as Kliewer & Sandler (1992) reported below, and Brown, Kaslow, Doepke, Buchanan, Eckman, Baldwin and Goonan (1993), studies with ill children using the SPPC are sparse.

'Do the personal characteristics of children protect them against the negative effects of stressful life events?' was the question posed by Kliewer and Sandler (1992). Locus of control (Nowicki & Strickland, 1973) and self-esteem (Harter, 1982) were examined as moderators of links between negative life events and psychological symptoms (The Child Assessment Schedule, Hodges, McKnew, Cytryn, Stern & Kline, 1982; and The Children's Depression Inventory, Kovacs, 1981). Children aged 8-16 years took part and comprised three groups: 85 children with divorced parents, 88 chronic asthmatics and 65 'non-stressed' children. Results indicated that personal characteristics buffer the relationship between stressful life events and psychological symptoms. The buffering effect of self-esteem was found only in girls and was accounted for by the interaction of self-esteem with locus of control. When faced with negative life events, Kliewer and Sandler found that girls who had both an external locus of control and low self-esteem showed the highest psychological maladjustment, i.e. they were found to be the most vulnerable group. According to

Garton and Pratt (1995) there is a negative relationship between the overall self-concept of a child and the frequency and effect of stressful events. They suggested that as stress increases in children's lives there is a decrease in their self-concept (N=1482, aged 10 to 15 years).

A study by Pretzlik, Sandalis, Karadimitrious and Sylva (1994) explored the relationship between children's coping with an everyday social problem and their perceived self-worth. Children described a problem recently experienced between themselves and their parents. Kidcope (Spirito *et al.*, 1991; Pretzlik & Hindley, 1993) and the SPPC (Harter, 1985) were administered during one-to-one interviews and completed by 80 children, 8 and 10 years of age. Significant associations were found between the children's perceived helpfulness and their feeling of Global Self-worth. The more helpful the children perceived the coping strategies to be, the more they liked themselves as individuals and the happier they were with the way they conducted their lives. As measured by the distress element of Kidcope, the more cross or angry the children felt about dealing with the described parental stressor, the lower their perceived Behaviour Conduct scores were. That is to say, the 'cross' children did not think they behaved well.

Bearing in mind that Kidcope is based on the Lazarus and Folkman (1984) transactional model of stress and coping, Lazarus (1990) hypothesised that the self-concept is one of the moderator variables in his transactional model of stress and coping, and it therefore is of interest to consider the association between children's way of coping and how they feel about themselves. One of the main reasons for assessing the self-concept in this thesis is to begin an empirical justification for this hypothesis.

2.2 Parents coping with a seriously ill child

It goes without saying that parents in general, and parents of seriously ill children in particular constitute a major part of their children's world. Parenting is an interactive process. The children influence the parents and the parents influence the child. Within a transactional model of development, the development of the child is viewed as a product of the continuous dynamic interaction of the child and the experience provided by his or her family and the social context (Sameroff, 1987).

Sensitive parents assume a large share of coping for the young children, even changing their response mode to fit a child's temperament, characteristics and current state of arousal (Field, 1985). With time parents assume less coping responsibility and ideally, this interchange will take place at a steady pace. As the child displays increased ability the parent withdraws support, and reduces the screening of potentially stressful events that the child may encounter. However, parental expectation sometimes exceeds children's abilities and the exchange may not always be smooth. What may then appear to be inadequate coping on the part of the child may on occasion be the result of abrupt or premature withdrawal of parental support (Azar & Rohrbeck, 1986).

To what extent are parent and child responses interdependent? The assumption is that mothers and fathers who cope 'well' have children who cope well and vice versa. Little, if any, empirical support for such a hypothesis has been published to date Also current literature is severely limited in its preoccupation with mothers' attitudes to their children's illness, and focuses on the mothers' diffuse responsibilities for practical aspects of the treatment regimen. There is an urgent need to involve fathers too in future research.

Both fathers *and* mothers, from single *and* two parent families, should take part in research projects. Procedures could be generated and ways then developed for mothers and fathers to manage and share the practical and emotional demands of caring for a child with a chronic disease.

Most early research on parents caring for a seriously ill child was conducted atheoretically (Beresford, 1994). More recent research is theory-driven based on *models of the family* (e.g., the social ecology theory, Bronfenbrenner, 1979; the family systems model, Kazak, 1987) and *models of stress and coping* (e.g., parental coping patterns, McCubbin, McCubbin, Patterson, Cauble, Wilson & Warrick, 1983; the process model of coping, Lazarus & Folkman, 1984; Thompson, Gil, Burbach, Keith & Kinney, 1993).

2.2.1 Parents coping with their child's illness

In the context of caring for a child with a long term illness, parental coping patterns have frequently been assessed using CHIP; the Coping Health Inventory for Parents (McCubbin *et al.*, 1983). Eiser and Havermans (1992) also used the CHIP and modified it to suit a British sample, and identified four dimensions: *Autonomy* 'getting away by myself', 'keeping myself in good shape', *Medical Care* 'believing that my child is getting the best medical care possible', *Social Support/Information* 'talking with other parents and learning about their experiences', and *Family Support* 'do things together as a family'. This self-report instrument, its structure, validity and reliability are described in Chapter 8.

In their study Eiser and Havermans compared coping patterns reported to have helped parents of children with longterm illness (diabetes, asthma, heart disease, epilepsy and leukaemia). One hundred and ninety eight couples in all took part and the scale was completed independently by fathers and mothers. One of the aims of

the study was to establish differences between the coping patterns the fathers and mothers used and found helpful, when dealing with their children's illness. Some differences were established - mothers tended to find coping items in general, and the Social Support and Medical Care dimensions in particular, more helpful than fathers. It was also established that results depended on the type of illness the children suffered from. Parents of children with epilepsy and heart disease found Autonomy to be more helpful than parents in the other groups, while parents of children with diabetes and epilepsy reported that Social Support was a more helpful coping pattern than did parents of children with asthma, heart disease and leukaemia. Parents of children with epilepsy and leukaemia were less likely to find Family Support helpful. The length of time since diagnosis (experience with the illness) made no significant difference to parental coping.

With a few exceptions (e.g. Kupst *et al.*, 1982, McCubbin *et al.*, 1983, Eiser & Havermans, 1992; Eiser, Havermans & Eiser, 1995) researchers paid more attention to the mothers' responses to their children's illness than to the responses of fathers, siblings and grandparents. This bias may partly be due to practical reasons. For instance traditionally mothers were more likely to be involved with child-care, less likely to be employed outside the home, and therefore were more frequently able to bring the child to hospital for in or outpatient appointments. Generally speaking, mothers were more often available and willing to take part in research studies than other family members. For example, in Thompson, Gustafson, Hamlett and Spock's (1992) study they looked at stress, coping, family functioning and the psychological adjustment of parents of children with cystic fibrosis. Fathers or mothers of 73 children (7-17 years of age) were asked to complete the self-report questionnaires. Of these 68 mothers and only 5 fathers took part. Since there were too few fathers for data analysis, the 68 mothers and their children made up the sample of this study while the fathers contribution was ignored by the researchers.

On the other hand, in Eiser *et al.*'s (1995) study 28 mothers and 23 fathers took part. The parents of 30 children with cancer were interviewed about their attributions of causality, and their perceptions of responsibility for the diagnosis and care of their child. Coping patterns which were reported to be helpful were assessed using the anglicised version of CHIP (Eiser & Havermans, 1992). Interesting differences between the two parent groups were found. Fathers were more likely than mothers to accept that there was no known cause for the child's illness. For fathers especially, the tendency to blame medical staff for failing to diagnose the condition of their child was earlier associated with lowered faith in medical staff and a reluctance to use medical staff as a source of support or information. However, there were no significant differences between mothers and fathers in their ratings of the helpfulness of different coping patterns when dealing with their child's illness. For example, both mothers and fathers gave lower ratings to Social Support/Information 'talk with other parents and learn from their experiences', than to Autonomy, Family Support and Medical Care.

According to anecdotal evidence observed in the hospital setting and reported by medical staff, a large proportion of fathers today do take on their share in caring for a seriously ill child. Nevertheless, the understanding and knowledge of the role played by fathers in families of chronically sick children, the impact of the disease on fathers and the way they cope is limited. However, issues related to the fathers' role in a family, where one of the members is an ill child, are increasingly being discussed. More women now work outside the home, and men may work shorter hours. There has also been a blurring in sex-role boundaries. Many men want and need to be more involved in the care and up-bringing of their children (Baruch & Barnett, 1986) and the need to be involved is perhaps especially acute when a child is ill.

2.3 Familial factors and coping

Having looked strictly at parental coping with their child's illness it is the broader issues such as the family, and the social climate of the family which will be considered in this section - starting off with four family models including the family process model which wherever possible are related to a child's illness and coping.

2.3.1 Models of the family and coping

First, social ecology is the study of the relationship between the developing child and the settings and contexts in which he or she is actively involved (Bronfenbrenner, 1979). As a theory *the social ecology model* is convincing and of interest to students and researchers alike. However, evaluating the relationship between the child and the contexts which influence his or her development proves more difficult.

The child is considered to be at the centre of a series of concentric rings. Each of the rings represents an increasingly large environment with which the child interacts. In families with ill children the *microsystem,* the ring that represents a child's most immediate setting, has been viewed as being of primary importance. Research on families' ability to adapt to an ill or disabled child have focused on the microsystem. For example, as discussed below, Wallander, Varni, Babani, DeHaag, Wilcox and Banis (1989) examined the resources, interactions and adaptations used by mothers to cope with stressful situations associated with the illness or disability of any of their children.

The ring outside the first ring is the *mesosystem*, which includes the interactive relationships in settings like schools, hospitals or neighbourhoods. Research on children with chronic illness has so far focused in isolation on the individual settings within each ring and has not yet explored the interfaces between systems and the

implications of these interfaces for ongoing care (Kazak & Rostain, 1989). The third ring, the *exosystem,* involves the settings which do not directly include the child, but have an indirect impact on the child's way of coping with the illness; for example the parents' work environment, and the school attended by siblings. However, the attention paid to this level has for the most part remained theoretical, possibly due to practical and methodological difficulties. And finally, Bronfenbrenner (1979) puts forward the *macrosystem.* The macrosystem consists of the environment in its broadest sense; aspects such as culture, and social and political policy which impact directly and indirectly on ill children.

Second, in their 1989 study, Wallander *et al.,* attempt to account for the processes underlying *mothers' adjustment to their child's disability.* Fifty mothers of physically handicapped children (aged 6-10 years) took part in the study. Using the semi structured interview format, a self-report questionnaire (The Family Environment Scale, Moos & Moos, 1981) and the Child Behaviour Checklist (Achenbach & Edelbrock, 1983), Wallander *et al.,* identify sets of risk and resistance variables. They include: intra-personal variables, seriousness and practical dependence associated with the illness or handicap, and the child's temperament and coping-style, and inter-personal variables for example, the mother's temperament and coping-style and social-cognitive variables, such as marital and family functioning, socio-economic status, family size and service utilization.

These variables are said to be inter-dependent and reciprocal in nature. For instance, intra-personal variables include characteristics of the disease and the child, as well as treatment demands and the child. Other less tangible variables are associated with the child, the varying degrees of difficulty experienced in administering treatment, and the child's willingness and readiness to co-operate. Those who are happy with regular schedules and routines may find it easier to fit in with the medical regime than those who prefer a less structured life-style. Inter-personal variables, including the

mother's temperament and coping style, are likely to influence ability to attract social support from others, or to determine whether professional help, such as social workers or clinical psychologists, are used to the utmost advantage. Social-cognitive variables, for example family size or socio-economic status, may influence mothers' perceptions of the severity of the social and economic constraints identified with the child's long or short term situation.

The model further assumes that families of a child with chronic disease are confronted by an increased number of potentially stressful situations. These are 'problematic situations requiring a solution or a decision-making process for appropriate action' (Varni & Wallander, 1988). It is not presumed that the presence of a child with chronic disease in the family necessarily results in maladjustment. To the contrary, considerable emphasis is placed on adaptation and resourcefulness of mothers' efforts to cope.

The way in which these stressors are dealt with is apparently dependent on personal competence (Varni *et al.*, 1989). This point has already been discussed and will be discussed again later in this thesis: coping is not solely dependent on the individual but is more likely to be influenced by the context in which the stressor occurs (Lazarus & Folkman, 1984).

This conceptual model of predictors of adjustment in mothers of sick or handicapped children (Varni & Wallander, 1988) is comprehensive. Up to now however, related research has focused only on the mother and has failed to extend to other family members. Most importantly it has omitted the central role of the ill child, for example using a well tested instrument (Child Behaviour Checklist; Achenbach & Edelbrock, 1983) children were observed in various situations, at home and at school, but notably they were not directly included through interviews or self-report methods.

A *third* family model is presented by Kazak (1992). Here the social ecology model is used and is combined with the concept of the *social context* in which the child and the family find themselves in. The social context, according to Kazak, is critical in understanding the long-term adjustment to paediatric illness and coping processes related to the illness. All family members are involved one way or another. She suggests that the social context related to this work should include the immediate and extended family and the wider environment. So far, Kazak's research has mainly addressed issues related to the social support of the family, that is to say social isolation of individuals and families, and the risk attached to them (e.g., Kazak, Reber & Carter, 1988; Kazak & Meadows, 1989).

While these models of the family offer important insight into the dynamics of the family and the way families react in time of stress, there are limitations. First, little attention is given to the role of factors external to the family and to intra-personal factors in mediating stressful situations. Second, such approaches have been slow to incorporate the notion of coping. The focus has been on family dynamics and the differential effect of family types on the experience of stress. Third, if and when coping is considered it has been in terms of strategies which seek to maintain family stability. Thus, the outcome of coping is defined in terms of the family as a unit, as opposed to the individual family member's well-being. Finally, how a child copes with chronic illness within the family unit has not yet been explored.

Eiser (1993) sums up recent research findings (Varni & Wallander, 1988; Perrin & MacLean, 1987 cited in Eiser, 1993) of theoretical models of adjustment as essentially 'multivariate' in nature. These models acknowledge that adjustment to a serious or long term illness is driven by a number of factors and as such, these multivariate models constitute a considerable advance over the more traditional, or linear models, which were based on the assumption that chronic disease necessarily and inevitably leads to maladjustment. For example, Thompson *et al.* (1993)

assessed the psychological adjustment of 78 mothers of children (7-17 years) with sickle cell disease. Their research provided support for a transactional stress and coping model and they concluded that moving away from a linear model of coping to a process model would be of future benefit.

The *fourth* and final model addressed here is *the process model of coping and the family*. As discussed in Chapter 1 coping efforts are influenced both by the characteristics of the person and characteristics of the situation in which he or she is coping. Some theories of stress and coping give greater emphasis to personal as opposed to situational factors. These theories tend to be more *trait oriented* and often are referred to as the coping style of a person (individual differences, i.e. age, sex), whereas others are more *process-oriented* and are referred to as situational (contextual, i.e. the illness or a medical procedure).

The Lazarus and Folkman (1984) process model - considered in detail in Chapter 1 and illustrated by Figure 1.2 - can be applied to investigate ways of coping both for parents and children, and the interaction between the two.

When parents' way of coping with their child's illness or disability is looked at, the process or transactional model of coping (Lazarus & Folkman, 1984) has several advantages over the three family based models discussed above. First and foremost, the process model was developed as a model of stress and coping, whereas in the family models coping was in a sense added as an afterthought. Second, the process model of coping is concerned with how the individual copes with a stressful situation and these findings can be followed up and related to other family members including the ill or handicapped child. Third, this model supports the role of intra-personal and socio-ecological factors in mediating stressful situations. And finally, the process model embraces the concept of the individual as actively and creatively seeking to manage stressful situations to the best of his or her abilities as and when they occur.

Although the theoretical and empirical treatment of the coping process has a history of examining how individuals cope, paediatric psychologists are aware that the ways in which children and adolescents cope with health and illness-related stress cannot be understood solely in terms of the individual. Coping with general life stress, coping with aversive medical treatments, and coping with chronic illness all take place within a social context. Contextual factors act both as a resource that helps and facilitates coping, and as an obstacle to it. Children function in a variety of proximal contexts, for example, the family, school and peer groups and broader contexts, such as neighbourhoods, cities and societies (Bronfenbrenner, 1986). Yet, according to Compas *et al.* (1992), the family stands out as an important element in the understanding of coping in paediatric populations.

Family characteristics and processes may be related to coping in a variety of ways. Families generate rules and enact regulatory processes that influence the coping strategies used by individual family members. For example, family members can serve as a resource for children who are coping with an illness and its treatment by providing *social support* and *information.* On the other hand, family members can also be an obstacle to the coping process by interrupting or constraining the coping efforts of a child, or by turning to the child for help in coping for themselves in ways that exceed the child's resources. In addition family members can serve as *role models* to the ill child who may copy their coping strategies. And finally, families operate as systems in which the coping efforts of individual family members may affect and be affected by the coping efforts of other family members in addressing a collective problem.

When building on Lazarus and Folkman's definition of coping (1984) it is essential to consider that coping efforts change according to the situation and time factors related to the specific stressor the individual is dealing with. Furthermore, both appraisals of stress and appraisals of coping resources are influenced not only by the

cognitive processes of the individual, but by the perceptions of the family members who are a part of and affected by the specific stressful situation. It is important not to forget the developmental and family contributions when considering the coping process and when studying children's way of coping with a serious illness.

While the more recent models of coping offer comprehensive listings of variables which may contribute to psychological outcomes, they are often less specific about the underlying processes involved. Family size, for example, can play a role. Where there are a number of other children in the family, anxiety about a sick child may be contained, simply because parents have other commitments. Yet, it is possible that parents with a large family may feel under ever greater stress. The demands involved in caring for other children restrict the time available to care for the sick child. It is therefore unclear how family size contributes to adjustment.

Research involving coping with a child with a serious illness has still a long way to go. No comprehensive account of coping processes related to the family of paediatric patients has been published to date. Eventually, coping by family members must be related to the ill child's coping, and attempts need to be made to answer the basic yet complex question 'Does parents and siblings' coping influence the way an ill child copes?'

2.3.2 The social climate of the family and coping

Traditionally, as mentioned above, research concerned with the impact of a seriously ill child on the family has been built on the assumption that the experience is associated with serious disruption, psychological, social and emotional, for both parents and children (for a comprehensive review see Eiser, 1985, 1993) and not so much with the coping resources within the family. The tendency today leans toward the understanding of children with chronic disease and their families as normal

people coping with specific stressors (Kazak, 1989) or as Perrin and MacLean's (1987, cited in Eiser, 1993) declared with regard to paediatric patients "Normal children in an abnormal situation" (p.1331).

The relationship between psychosocial stress and adaptation, when dealing with a child with a serious illness, is hypothesized to be moderated by the use of certain coping strategies. Wallander *et al.*'s work (1988, 1989) with mothers of physically handicapped children has contributed towards a complex conceptual model (Section 3.3). Research following on from this model has looked specifically at the adaptation and availability of resources of mothers of seriously ill or handicapped children.

In their 1989 study for example, Wallander *et al.* considered the association between the social environment and adaptation in mothers with physically handicapped children. To obtain information about the children's disability, daily life and family situation, semi-structured interviews were completed by 50 mothers. A number of instruments measuring family support, marital satisfaction and available social network were administered to the mothers. To assess the children, the mothers completed the Child Behaviour Checklist (Achenbach & Edelbrock, 1983). The children's teachers completed the same checklist and were also asked to list primary services available to physically handicapped children and their families.

The social environment was measured by the Family Environment Scale (FES, Moos & Moos, 1981). Significant associations were found between the social environment of the family and the mental and social functioning of the mothers. However, the mothers' physical health was not significantly related to the social environment, neither was the children's disability status related to maternal adaptation. At a more general level, Wallander *et al.* suggested that these results support the notion that psychosocial outcomes in mothers of handicapped children are probably better predicted by psychosocial factors than by aspects of the children's physical condition.

A shorter period of marriage and a smaller family, according to results reported, may contribute to a more active social life for these mothers. Research focusing on the impact of a social support network on the adaptation of parents to chronically ill or handicapped children has been reported by Kazak (1988) and Kazak, Reber and Snitzer (1988) and is discussed below.

The Family Environment Scale (Moos & Moos, 1986) is the most widely used and confirmed self-report measure for family functioning. It taps an individual's perception of the family environment that characterises his or her family, but it does not capture the family's interactive reality. The four dimensions and ten factors which make up the FES are reported in Chapter 9 - details of validity and reliability are also described.

Through the collaboration of Varni and Wallander a multivariate conceptual model had been developed based on the family systems theory. In a recent publication Varni, Katz, Colegrove and Dolgin (1996) reported to have looked at family function predictors of adjustment in children with newly diagnosed cancer (5-13 years of age). Arrivals at two hospitals in California were recruited over a four year period. A total of 62 parents, 61 mothers and one father, took part. The parents were administered the assessment instruments at three points in time - within a month after diagnosis, then six months post-diagnosis and finally nine months post-diagnosis.

Family functioning was measured through the FES (Moos & Moos, 1986) and the child's psychological and social adjustment was assessed using the Child Behaviour Checklist - Parent Report Form (Achenbach, 1991). Both instruments were completed on each of the three occasions. The main aim of the study was to test the predictive effects of family functioning on the adjustment of children with cancer. Varni *et al.* claimed that higher Cohesion and Expressiveness in the family were significantly predictive of lower psychological distress and higher social competence.

The Relationship dimension (Cohesion, Expressiveness and Conflict, i.e. the degree of commitment, help and support members provide for one another) was consistently predictive of child adaptation, both at the time of assessment and in the future, i.e. at 6 and 9 months after the illness was first diagnosed. Family functioning as a whole was more predictive of child adjustment at the time of assessment than later on. The authors suggest that these findings show current family functioning to be more important for children with newly-diagnosed cancer at six and nine months than predicting family functioning from the time of the diagnosis.

A major focus of the Varni *et al.* study was an attempt to identify potentially modifiable risks and protective factors that might help the adjustment of these children. However, this neatly designed study, based on the multivariate conceptual model (Wallander *et al.*, 1989) and developed expressly to explain the differences in adaptation by chronically ill and handicapped children, omitted the all important views and perceptions of the children. Apart from the observation schedule, which was completed by the parents, children did not take part - neither self-report or interview methods were applied. Both the family functioning and the child adjustment measures were based on parent reports, but as already mentioned 61 mothers completed the study and one father took part.

A study using similar methods was reported by Billings and Moos as early as 1983. Interestingly during this period of thirteen years methodology has changed little. Future studies related to children's functioning with illness would surely benefit from third party observations and children's self-report data being included.

2.3.3 The family structure and coping

When reviewing literature on parents and ill children a further weakness becomes apparent. Research of this type is traditionally based on conventional two parent families. It is well documented that the make-up of the contemporary family has changed dramatically in recent years (Robinson, 1991). The assumption that a family consists of mum, dad and their children is no longer valid.

Looking after a child with a chronic disease impacts significantly on the level of practical and emotional stress of the whole family. This stress has many consequences for the parents' relationship with each other. Not only do they have to deal with the routine difficulties shared by parents of young children and adolescents everywhere, but they also have to acknowledge that their son or daughter may have a limited life-expectancy and/or be subject to many painful experiences and reduced opportunities.

There has been a widespread belief that having a child with a chronic medical condition is a highly stressful experience which may contribute to marital disruption, divorce, or psychopathology in both parents and children. Research provides fairly strong evidence against this notion of inevitable family disruption and points instead to a broad range of functioning (Sabbeth & Leventhal, 1984). Thus, no causal link between the presence of a child with a chronic disease in the family and subsequent parental divorce has been established. Nevertheless, given the incidence of divorce in the general population, it is clear that many children with chronic disease are brought up in single-parent families.

According to Eiser (1993), little attempt has been made to consider the special problems confronting families with seriously ill children. To make matters worse, for the purpose of statistical analyses and to reduce variability, single parent families are

known to have been excluded from samples, Thompson *et al.*'s (1992) research being an exception. In their study 54 of the mothers were reported to be married and 14 were single parents. The question of whether this variable altered the result of the analysis was addressed and no significant difference was established between the subgroups of mothers who were married and those who were not. All 68 mothers and their children were therefore treated as one subject group.

2.4 A final comment

Methodologically it is common to compare ill children with a healthy group of children. This in itself sends an implicit message that those with a serious illness are somehow abnormal (Kazak, 1989), rather than simply children coping with very special circumstances. It is unlikely that any single aspect of an illness will be identified as crucial in determining adjustment of child or family (Eiser, 1992). The more optimistic approach appears to involve greater emphasis on the family's own perceptions of the child's illness, and not so much on comparing an ill group with a healthy group of children. Work along these lines is relatively rare.

In considering the impact of serious illness on children and their families, it is necessary that we develop 'child-centred' approaches, and attempt to determine how children cope with their illness related experiences. Too much work is concerned with *either* the child *or* the family. New methods and analysis *across* the child and the family are necessary to enable clarification of the complex inter-relationships which arise when a child is seriously ill.

2.4.1 Relating the above to this thesis

In the first part of this chapter some characteristics of children were considered and where possible were related to findings of children's coping with their illness or a medical procedure (Sections 2.1).

A brief yet complex discussion of literature related to the family and ill children coping was presented in Sections 2.2 and 2.3. Its relevance to this thesis may not, at the first glance, be altogether obvious. However when looking at various parts of the literature reviewed it becomes apparent that the relationship between parents, the family environment and children's way of coping is in urgent need of investigation.

In the absence of any definitive prior research related to the influence of the social environment of the family on the child's way of coping, and the way parents cope with their child's illness and its influence on the child's way of coping, no specific hypotheses have been generated regarding the predictive ability of parents and family to assess children's ability to deal with different stressors. These dimensions and their possible influence on the children will be explored in Studies 4, 5 and 6.

It is intended that the six empirical studies reported in this thesis, their strengths and even their limitations, will provide a thorough examination of children coping with a serious illness.

PAGE
MISSING
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ORIGINAL

CHAPTER THREE
MEASURING CHILDREN'S COPING
Study 1

Kidcope, the instrument used in this study, is a checklist that measures children's cognitive and behavioural *coping strategies* as well as how *helpful* children perceive each coping strategy to be when dealing with a stressor. It also assesses the amount of *distress* children and young people feel about a specific stressor.

The three aims of this study were:

To adapt Kidcope to younger children by producing a *colour coded response scale* and by modifying the language of the checklist to suit a British sample.

To compare the responses of children who used the *colour coded* response scale with the original Kidcope where *words* only are used and to validate the colour coded response scale.

To *test-retest* the modified Kidcope to suit a younger, British sample.

All results in this chapter are based on the Kidcope Checklist.

3.1 Kidcope: the checklist

The Kidcope Checklist was developed in the USA by Anthony Spirito *et al.* (1988) and is modelled on the Ways of Coping Questionnaire for adults (Folkman & Lazarus, 1980; revised 1984). The origin and structure as well as the reliability and validity data will be discussed first. This is followed by the method section. The second part of the chapter consists of the results related to the three main elements which make up the semi-structured questionnaire: distress, coping strategies and helpfulness. Finally a summary of the results is provided.

3.1.1 The coping strategies

A pool of 24 coping items for young people was generated. Those items were then used with a population of 134 healthy adolescents. Factor analysis extracted items relevant to making up ten coping strategies which were named as: *Distraction, Social Withdrawal, Cognitive Restructuring, Self-criticism, Blaming Others, Problem Solving, Emotional Regulation, Wishful Thinking, Social Support* and *Resignation* (Table 3.1).

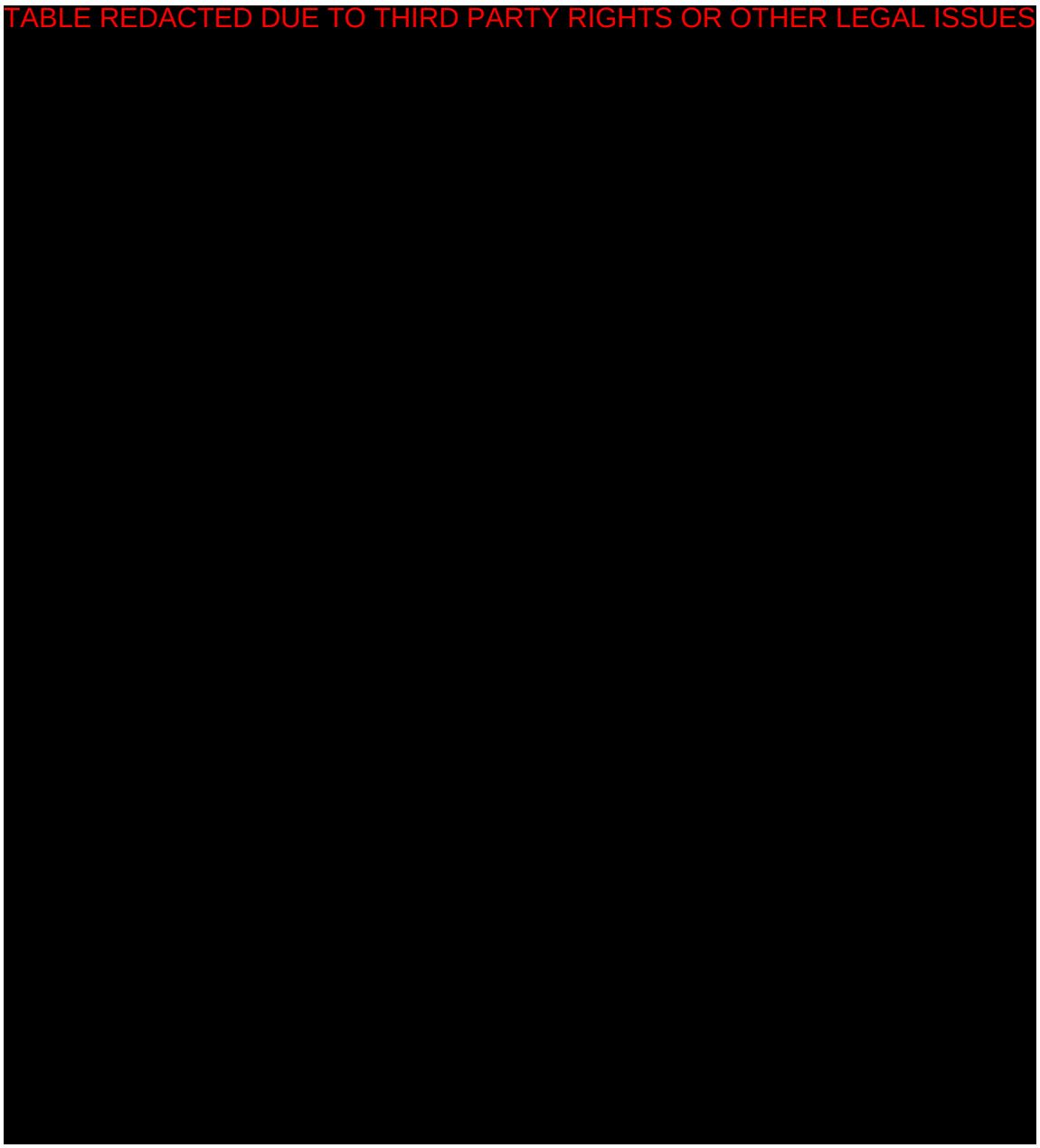
Prior to the present study the Kidcope Checklist involved children from 9-18 years. There are two versions: Kidcope for Younger Children 9-12 years (Spirito *et al.*, 1991) and Kidcope for Older Children 13-18 years (Spirito *et al.*, 1988). Examples of the two versions are included in appendix. The scale for Younger Children, derived from the scale for Older Children, was first adapted by Spirito *et al.* in 1991. The language was simplified and the list of coping items was increased from 11 to 15 while keeping the number of coping strategies to ten. It is this version for Younger Children that has been adapted to a still younger British sample (children from 7 years) in Study 1 and is reported in this chapter.

In Study 1 seven changes were made to the original Kidcope to accommodate British children (Table 3.1). Expressions such as *pretty much* were changed to *a lot*, *TV* to *telly*, I stayed by *myself* to I stayed *on my own*, *fix* to *sort out*, *yell* to *shout* and another *fixed* to *solved*.

When completing Kidcope the child or young person is either given a scenario, for example 'being grounded by the parents' (Spirito *et al.*, 1991) or is asked to choose a *specific stressor*, also called a 'scenario' within a given *context*. The choice of the context is made by the researcher and depends on the research question. As mentioned above, the choice of the stressor within the nominated context, is made by the children. For example, a group of school children were asked: 'Can you describe a recent problem you have had with one or both of your parents?' (Pretzlik

et al., 1994). The children then recalled a stressor related to that context. The specific stressor is kept in mind when answering questions throughout the rest of the procedure.

Table 3.1 The Kidcope Checklist: 15 coping items generate10 coping strategies (Spirito et al., 1991)



3.1.2 Self-reported distress

A specific scenario having been described, the perceived level of *distress* related to the scenario is rated. Three questions are put to the child:

Did that time (related to the described problem) *make you feel*

a) *nervous* or *anxious*?

b) *sad* or *unhappy*? and

c) *cross* or *angry*?

These questions are answered with:

not at all (1), *a little* (2), *somewhat* (3), *a lot* (4) or *very much* (5).

The scores of these three elements (nervous/anxious, sad/unhappy, cross/angry) are added to create the self-reported distress score, giving a possible range of 3-15 in each context.

3.1.3 Perceived helpfulness

The child rates each of the coping items according to whether he or she used a particular item and third how *helpful* he or she perceived the coping item to be. The coping item (Table 3.1 and Appendix IV) is answered by a simple *yes* or *no*.

When a child answers *yes* to having used a coping item (15 coping items make up the ten coping strategies), he or she is then asked:

How much did it (that coping item) *help?*

a) *not at all* (1)

b) *a little* (2) or

c) *a lot* (3)

When a child answers with *no*, for not having used a certain coping item, there is no helpfulness score.

The missing helpfulness items are coded as missing and not as zero scores, leading to fewer helpfulness items than coping strategies. That is to say that when a child fails to use a coping item, the *How much did it help?* question is not asked. For those coping strategies that have two items, only one of the answers is scored. The answer counted is the one perceived as most helpful by the child and the overall data are reported as mean helpfulness scores.

3.1.4 Validity and reliability

The validity of a test concerns *what* the test measures and *how well* it does that. Validity provides a check on how adeptly the test fulfils its function. When researchers talk about the reliability of an instrument they usually mean and refer to *consistency*.

3.1.4.1 Validity of Kidcope

In their 1988 paper Spirito *et al.* reported the validity of the coping strategies. In defence of their work, Spirito *et al.* compared Kidcope with two previously standardized measures of coping, namely the Coping Strategies Inventory CSI (Tobin, Holroyd & Reynolds, 1984) and the Adolescent-Coping Orientation for Problem Experiences Inventory ACOPE (Patterson & McCubbin, 1983).

Both the CSI and the ACOPE inventory are long and comprehensive questionnaires. The CSI is a 72-item scale with a 5-point Likert-type format (validity of the CSI has been reported by Tobin *et al.*, 1984). Factor analysis produced with eight factors similar to the Kidcope coping strategies. They are *Problem Solving, Cognitive Restructuring, Emotional Expression, Social Support, Problem Guidance, Wishful Thinking, Self-criticism* and *Social Withdrawal.* The ACOPE is designed for adolescents and consists of 54 items each rated on a 4-point Likert-type scale (validity of this instrument is reported by Patterson and McCubbin, 1983, in Spirito *et. al.*, 1988). The 54 items make up 12 factors and these factors include *Seeking*

Diversion, Developing Self-reliance, Avoiding Problems, Developing Social Support and *Seeking Professional Support.* Two studies comparing the two coping inventories and Kidcope were reported (Spirito *et al.*, 1988).

First, the similarity of several items and factors on the CSI and Kidcope made it possible to compare the two tests. The correlation between the Kidcope and the CSI format, using 42 school children aged between 14 and 15 years of age, ranged from a low correlation where r=.33 to a high correlation where r=.77 for the eight factors. Seven out of the eight factors were reported to be significantly related (p<.05). It should be remembered that although these associations are statistically significant, confirming a strong similarity between the two scales may be premature as the explained variance ranges from 11% to 59% and leaves a large percentage still unaccounted for.

Second, Spirito *et al.* (1988) administered Kidcope and ACOPE to a group of school children. Kidcope evaluations for the validity analyses were carried out using a personal stressor that had been encountered by the children during a recent period. Forty nine young people between 14 and 15 years of age completed both Kidcope and ACOPE. A positive association between some of the Kidcope coping strategies and the ACOPE factors was found; six of the twelve factors were significantly correlated (p<.05). Overall, as discussed above, the factors on ACOPE are less similar to the Kidcope coping strategies than the factors on the CSI. When the coping factors are similar between the two tests, as for example with the *Seeking Diversion* subscale of the ACOPE and with the *Distraction* coping strategy on the Kidcope, a modest correlation was obtained (r=.62, p<.001, N=49) and accounted for 38% of the variance. Not surprisingly, where the factors on the questionnaire are similar the results show reasonable agreement and thus validity between the two measures. However, as validity must be established for any psychological test, more studies concerned with the validity of Kidcope need to be undertaken.

Validation of the *distress element* and the *helpfulness part* of the Kidcope Checklist was not reported by Spirito *et al.* (1988, 1991, 1995). Validation for the distress element however has, for the first time, been established in this study using observational and self-report methods (Pretzlik & Sylva, 1995). The results are reported in Chapter 6.

3.1.4.2 Reliability of Kidcope

Kidcope is a measure developed to assess a cognitive *process*. Coping is viewed as a process as opposed to a stable personality trait and it is the process of coping that is explored here. Test reliability is the consistency across test scores obtained by the same person when retested with the identical test or with an equivalent form of the test. It can therefore be argued that a *reliable* instrument measuring *coping* is a contradiction in terms due to the fluency of an individual's way of coping within and across varying problems. The impossibility of repeating exactly same situation in which a child copes with a stressor, adds to the difficulties of establishing reliability. However, Spirito *et al.* (1988) reported undertaking two successful test-retest studies using the Kidcope Checklist.

Modest to high correlations were obtained when subjects rated the same stressor three days apart (r=.56 to r=.75, N=60). The subjects, 60 young people from 15 to 18 years of age, completed Kidcope on two separate occasions *three days* apart. On the second occasion they were asked to recall the *problem* they had described earlier and to complete Kidcope according to how they coped with that event. These correlations may have been influenced by the short time factor of three days between the two administrations as described by Spirito *et al.* (1988). On the other hand, the fact that the *same* scenario was related and used as the basis to answer the same question twice within a short period of time is surely a contributory factor in the test-retest 'stability'. Familiarity of the stressor and remembering what was said on the previous occasion should be accounted for before confirming reliability.

Low test-retest correlations (r=.15 to r=.43, N=142) were reported in a second study. The sample consisted of 142 healthy children whose ages ranged from 13 to 16 years. A personal stressor with which an individual had coped with in the preceding month was selected and reported. *Ten weeks later* the same group of people was asked to complete the Kidcope once more in response to *another stressor,* eliminating not only remembering the answers from the previous interview but also familiarity with the stressor. However when this method, more closely linked to the transactional model of coping (Lazarus & Folkman, 1984), was used, reliability was not confirmed.

If coping is viewed as a process with only limited stability within individuals over time and if it is affected by the social and environmental context, then measuring an individual's coping strategies after a considerable period of time using a different stressor, is expected to result in weak test-retest correlations. Therefore, to demonstrate reliability when using the Kidcope Checklist across different contexts will be a daunting task.

Reliability for the distress element and the helpfulness part of the Kidcope Checklist were not reported in previous studies.

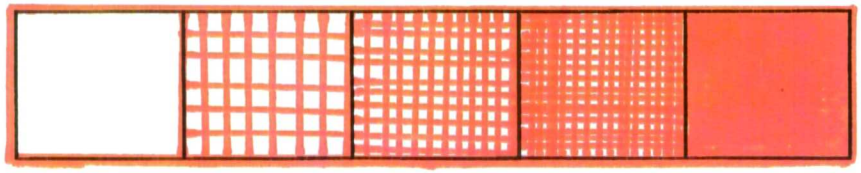
THE METHOD

In Study 1 Kidcope was adapted to a younger group of children by producing a colour coded response scale for both the distress element and the helpfulness part of Kidcope (Figure 3.1). Two conditions - the use of the colour coded response sheet first and the original words second and vice versa - were applied eight days apart to validate this newly designed part of the instrument.

The modified Kidcope was completed four times by the same child (with a the common or everyday problem and a problem related to a recent illness) to assess

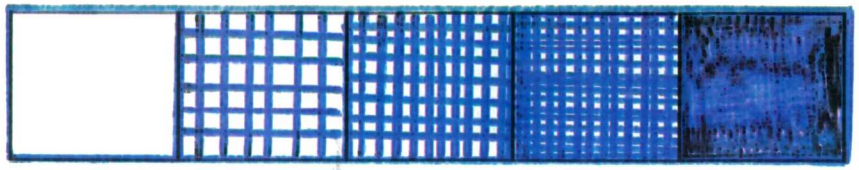
YOUNGER CHILDREN
Colour-coded response strips

Did it make you NERVOUS or ANXIOUS?



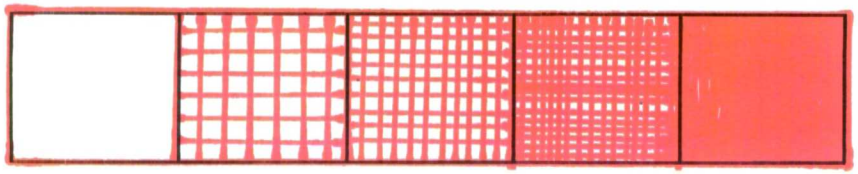
Not at all A little Somewhat A lot Very much

Did it make you SAD or UNHAPPY?



Not at all A little Somewhat A lot Very much

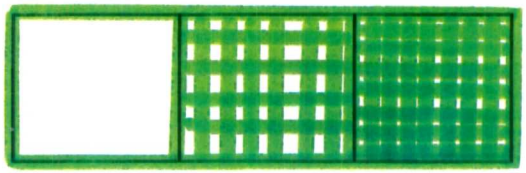
Did it make you CROSS or ANGRY?



Not at all A little Somewhat A lot Very much

YOUNGER CHILDREN
Colour-coded response strip

HOW MUCH DID IT HELP?



Not at all A little A lot

Figure 3.1 The colour coded response strips

reliability of the three main parts of the instrument; distress, coping strategies and helpfulness and to validate the colour coded response scale.

3.2 The colour coded response strips

The colour coded response strips were designed by the researcher and were used for the first time in an earlier study by Pretzlik and Hindley (1993). It was found that children as young as five managed them satisfactorily. However, validity and reliability were not tested.

The colour coded response strips make the *three distress elements* and the *helpfulness part* of the Kidcope Checklist visual for children and help them respond to how they feel about a problem, and how helpful they perceive a coping strategy to be. The two Likert-type scales (1-5 for the three distress elements; 1-3 for the helpfulness part) are represented by graduated scales in different colours. The colour selection was a personal decision taken by the researcher. On the *orange* scale a child can indicate how nervous or anxious he or she felt about the problem, on the *blue* scale how sad or unhappy and on the *red* scale how cross or angry he or she felt. The scale ranges from an 'empty' box through to a 'full' box. The *green* 3 point scale ranges from 'empty' to 'almost full'. The procedure is described in Section 3.4 and the scales or strips are represented in Figure 3.1.

3.3 The Sample

To test the reliability and validity of Kidcope and the colour coded response strips children from three London primary schools took part in this study.

A total of 40 children were picked at random by their class teacher. From a methodological view point it could be argued that a teacher 'picking a pupil' is not

altogether 'at random' as he or she might have picked them to suit class work and the timetable, for example.

Table 3.2 The composition of the school children (the sample)

	School children		
London schools	boys	girls	total
Honeywell	9	6	15
Orchard	4	4	8
Fox	4	5	9
total	17	15	32
age in months:			
range	84-123	85-121	84-123
mean	99.50	100.10	99. 70

The 40 children completed Kidcope during the first one-to-one interview session. Thirty two of them were available to complete Kidcope one week later. Five girls and one boy were ill and two boys had gone on a family holiday. The boys (n=17) and girls (n=15) who took part were aged between 7 and 10 year. Table 3.2 presents the composition of the sample.

It has been found that the Kidcope Checklist is best administered on a one-to-one basis thereby enabling the researcher to read each item with the child (Pretzlik & Hindley, 1993). The children were given a choice of writing down the scenarios and ticking the distress and coping items themselves or getting the researcher to do it.

3.4 Measuring children's coping: the procedure

The *colour coded response strips,* described and illustrated by Figure 3.1, were counterbalanced by the use of *words from the original Kidcope Checklist* during the first session (day 0) and the second session (day 7). All interviews were carried out by the same researcher. An example of Kidcope is given in Appendix IV.

During **Session 1** the child was first asked to choose and to recall two personal stressors; one related to a *common* or everyday problem and another related to an *illness*. The researcher asked: 'I am trying to find out how children deal with different problems. Think of a time when you had a problem that bothered you. Can you describe this problem?' Descriptive examples of stressors reported by children who took part in this study are recorded in Table 3.4. The order of the problem type, common or illness related, was alternated.

Secondly the child rated the degree of *distress* related to the stressor (1-5 Likert-type scale). The colour coded response sheet was used to help children report on the three distress elements as measured by Kidcope (Figure 3.1). The three elements make up the total distress score felt by a child when referring back to the described scenario (stressor).

The researcher asked each child:
Did that time (related to the described scenario) *make you feel*

a) *nervous* or *anxious?* ***orange***
b) *sad* or *unhappy?* ***blue***
c) *cross* or *angry?* ***red***

The children used either the colour coded response strips (condition 1) or the original words first (condition 2) to answer the questions.

Thirdly, each child was asked if her or she had used any of the 15 coping items (Table 3.1), for example, *Did you try and see the good side of things?* or *Did you try and sort out the problem by thinking of answers?* The coping items were answered simply *yes* or *no* and generate the coping strategies.

Fourthly, if a coping item was reported to have been used, i.e. answered with yes, the child was then asked: *How much did it help?* rating the coping item according to how helpful he or she perceived it to be. The helpfulness part is scored on a 1 to 3 Likert-type scale ranging from *not at all helpful* and *it helped a little* to *it helped a lot.* The original words only were used or to make the answer visual and therefore easier for the children, the ***green*** colour strip was applied.

Table 3.3 A summary of the procedure

	20 children 7-8 years old		20 children 9-10 years old	
sessions	CONDITION 1	CONDITION 2	CONDITION 1	CONDITION 2
(1) day 0	10 using the colour strips	10 using words only	10 using the colour strips	10 using words only
(2) day 7	10 using word only	10 using the colour strips	10 using words only	10 using the colour strips

During **Session 2**, after a gap of seven days, and with the help of the researcher each child recalled the personal stressor he or she talked about during the first interview session. Kidcope was again completed twice with reference to the same stressors, one a common or everyday-life problem and another an illness related problem, and the order was reversed.

The original stressors were referred to throughout Session 2. Conditions, that is to say the day of the week, the time of day, the order in which the children came to talk to the researcher and the place in which the interview took place were kept the same to control as many variables as possible.

RESULTS

The results from the Kidcope Checklist covering distress, coping strategies and helpfulness, are presented in this part of Chapter 3. Thirty two children completed the semi-structured interviews twice and referred each time to their selected stressors in the common and illness related situation (context). It was relevant to use both condition 1 and condition 2 for the distress and helpfulness part of Kidcope only - for condition 1 the colour coded response sheet was used on day 0 and the original words on day 7, for condition 2 the order was reversed.

First, children's *distress* is presented (Section 3.7), second, the *coping strategies* used by the children (Section 3.8) are compared and third, it is reported to what extent the children found a specific coping strategy *helpful* (Section 3.9).

Throughout this thesis *the situation* in which the child dealt with the stressor is also referred to as *the context.*

The data presented in this study (Study 1) are of nominal and ordinal nature. Therefore, analyses were carried out using methods for distribution-free data.

3.5 Reliability and validity

Reliability means consistency, that is to say, the extent to which the measure remains constant for an individual child if he or she was repeatedly tested under the same

conditions. Lack of reliability in a measure adds to the random effect of the data. Two theoretical constructs may be in close agreement, but if the instruments that measure them are unreliable, then the correlation between the two instruments is limited. In this study in order to examine *the reliability of Kidcope (distress, coping strategies* and *helpfulness)*, two sets of data were obtained by repeating the one-to-one interview with each child.

Validity refers to the association between the operational procedures used in an instrument and the theoretical construct which is supposedly being measured. Tests are valid when they measure what they are intended to measure. As with reliability, to investigate the validity of an instrument, two scores for each child have to be obtained. In this study the children were put into two groups, one of which used condition 1 and the other condition 2. *The validity of the colour coded response sheet,* applied when talking to the children about their feeling of *distress* and also used for the *helpfulness* part of the Kidcope Checklist, was assessed.

Validity of the distress element was confirmed in Study 3. A positive relationship between children's self-reported distress and the distress behaviour observed by the researcher was found (r=.56, p<.001, N=53), accounting for 31% of the variance. This result is reported in Section 6.6 and demonstrates the validity of children rating their distress during a medical procedure (Pretzlik & Sylva, 1995).

3.6 The scenarios

In the first interview each child described a common and an illness related stressor and completed Kidcope accordingly. The children were asked to think of a time when they had a problem that bothered them, an everyday-life problem related to home, school, friends or anything else that had worried them (referred to as the *common context*). They were also asked to think of a recent period when they did not feel well, when they had been ill or sick (referred to as the *illness related*

context). The exact scenario was recalled in a second interview one week later, when the Kidcope Checklist was completed as before. Some descriptive examples of scenarios referred to as stressors are recorded in Table 3.4.

Table 3.4 Common and illness related scenarios (stressors): descriptive examples

Stressors in the common or everyday context
Robert 7 My brother and I fight a lot. One day he was playing with the computer. We both wanted to play the same football game. He is so annoying and horrible and he is bigger than me.
Harriet 8 'Medals' is my hamster - he is sweet. I had him since my birthday and one day he got lost under the floorboards. He was squashed for a long time and I worried a lot but after I called him lots and lots of times he came and I pulled him out.
Annice 9 I forgot the picture I drew for the assembly, you know like the one we had this morning, the day before. I left it at home and had to fill in the background in a hurry.
Gemma 10 I tripped over a piece of wood in the playground. It was paved. I broke my shoe strap and hurt my knee pretty badly. It hurt and I was embarrassed and had to limp home.
Stressors in the illness related context
Ramsey 7 I had chicken pox not very long ago. I looked all spotty. The worst thing was that my head went round and round.
Anthony 8 After Christmas I had tonsillitis and I threw up six or seven times. I made the bathroom all dirty and sticky and I didn't like it. I felt awful.
Maya 9 I banged my teethes when the door slammed in my face. I was bleeding and it hurt but luckily I didn't loose them. No, it was Dad who slammed it but he did it by mistake. But it hurt.
Karama 10 I had to go to hospital for one night. I was feeling hot and cold and dizzy. I was pale and tired and my Mum said we had to go. She was very worried and I did not like leaving home. They found nothing wrong with me.

3.7 Kidcope: self-reported distress

No previous research by Spirito *et al.* (1988, 1991, 1995) examined the validity and reliability of the distress elements of the Kidcope Checklist.

3.7.1 Reliability and validity in the common context (the everyday-life scenario)

In the first interview children described a common stressor. The exact scenario was repeated in a second interview one week later. Some examples are reported in Table 3.4. Results of the *reliability* of the self-reported distress and *validity* of the colour coded response sheet are assessed and presented in Table 3.5 and illustrated by Figure 3.2.

Table 3.5 Self-reported distress as measured by Kidcope: time and condition in the common context

		COMMON CONDITION 1 (n=17) mean scores		**COMMON** CONDITION 2 (n=15) mean scores	
		day 0	**day 7**	**day 0**	**day 7**
colour^	anxious	2.94			2.73
	sad	2.77			3.00
	cross	3.65			2.73
	distress	9.35			8.47
word^	anxious		2.65	2.53	
	sad		2.71	3.47	
	cross		3.71	2.93	
	distress		9.06	8.93	
colour-word^^	anxious	0.29		0.20	
	sad	0.06		-0.47	
	cross	-0.06		-0.20	
	distress	0.29		-0.46	

^ S.E. standard errors for the three distress factors in the two conditions range from 0.361 to 0.473; and for total distress from 0.727 to 0.925

^^ S.E. standard errors for the differences in the three distress factors range from 0.206 to 0.405; and for total distress 0.435 and 0.467 respectively

Small differences were found between children using condition 1 and condition 2 as reported in Table 3.5. The Mann-Whitney U test for two independent samples and distribution free data was applied to see if a distinction could be made between the children who used colour first and words second and the children who used words first and colour second. No significant differences were found between the two conditions and the three distress elements and total distress in the common context.

Validity of the colour coded response sheet was established, suggesting that in future studies, children from 7 years of age, can be presented with either the colour strips or the original words whenever the Kidcope Checklist is used.

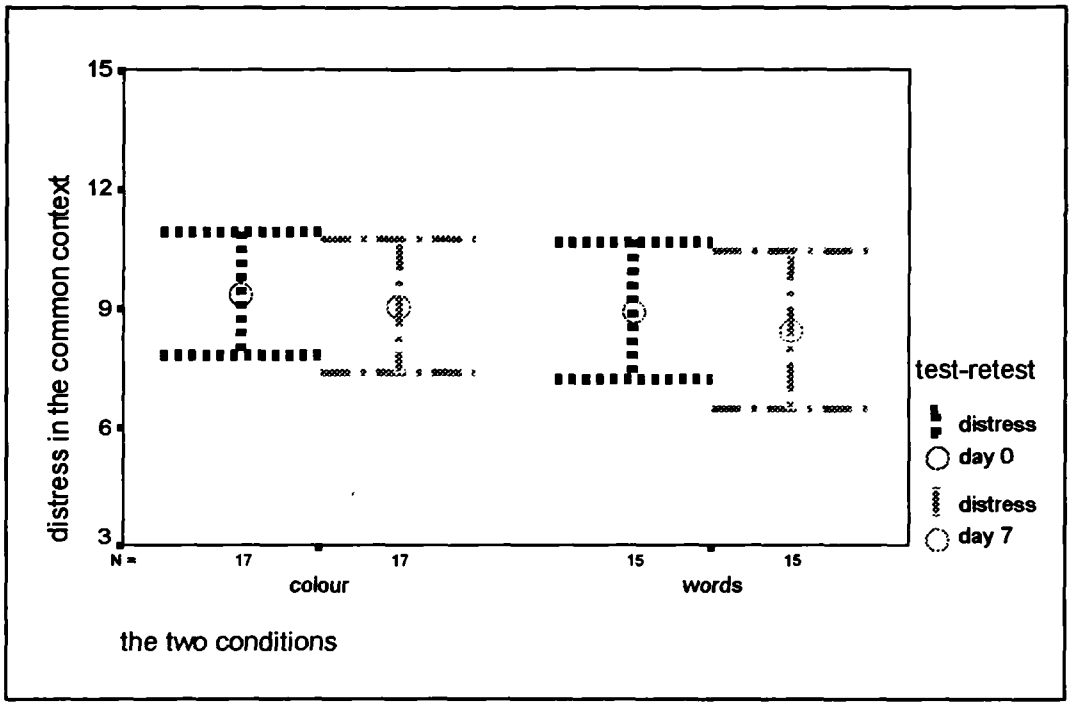


Figure 3.2 Self-reported distress: test-retest and two conditions in the common context (N=32)

Spearman's rank correlation was applied to see if the three distress elements and total distress reported within the common context on the first day and again one week later were associated. Significant relationships were found: nervous/anxious ρ=.74, sad/unhappy ρ=.69 and cross/angry ρ=.79, all p<.001.

An excellent correlation for test-retest is said to be r=.90 (Howell, 1992). In this study, where condition 1 and condition 2 (the colour coded response sheet and the original words) are included in retesting Kidcope, a correlation of around r= .80 can

also be said to be excellent. Spearman's *rho* is the same as Pearson's *r* for ranked data, with the same correlations but corrected for ties.

The relationship between the self-reported distress mean scores on day 0 and day 7 in the common context is illustrated in Figure 3.2; the two conditions are also represented. Reliability of the distress element in the common context was established. An excellent correlation between total distress on day 0 and day 7 in the common context confirms reliability (ρ=.84, p<.001, N=32).

Having established reliability of the distress element and validity of the colour coded response sheet in the common context, self-reported distress in the illness related context is considered next.

3.7.2 Reliability and validity in the illness related context (the recent-illness scenario)

In the first interview children described not only a common stressor but also an illness related stressor. The exact scenario was repeated in a second interview one week later (for a descriptive example see Table 3.4). Results of the *reliability* of the self-reported distress and *validity* of the colour coded response sheet are assessed and presented in Table 3.6 and illustrated by Figure 3.3.

Table 3.6 Self-reported distress as measured by Kidcope: time and condition in the illness related context

		ILLNESS RELATED CONDITION 1 (n=17) mean scores		ILLNESS RELATED CONDITION 2 (n=15) mean scores	
		day 0	day 7	day 0	day 7
colour^	anxious	2.35			2.40
	sad	2.24			3.13
	cross	1.94			2.27
	distress	6.53			7.80
word^	anxious		2.35	1.93	
	sad		2.35	2.67	
	cross		2.24	1.87	
	distress		6.94	6.47	
colour-word^^	anxious	0.00		0.47	
	sad	-0.12		0.46	
	cross	-0.29		0.40	
	distress	-0.41		1.33	

^ S.E. standard errors for the three distress factors in the two conditions range from 0.267 to 0.425; and for total distress from 0.749 to 1.048

^^ S.E. standard errors for the differences in the three distress factors range from 0.165 to 0.319; and for total distress 0.454 and 0.347 respectively

Small variations are reported in Table 3.6 between children using condition 1 and condition 2. The Mann-Whitney U test was applied to look for differences between the children who used colour first and words second and the children who used words first and colour second. No significant differences were found between the two conditions and the three distress elements and total distress in the illness related context (Figure 3.3). Validity for the colour coded response sheet was established.

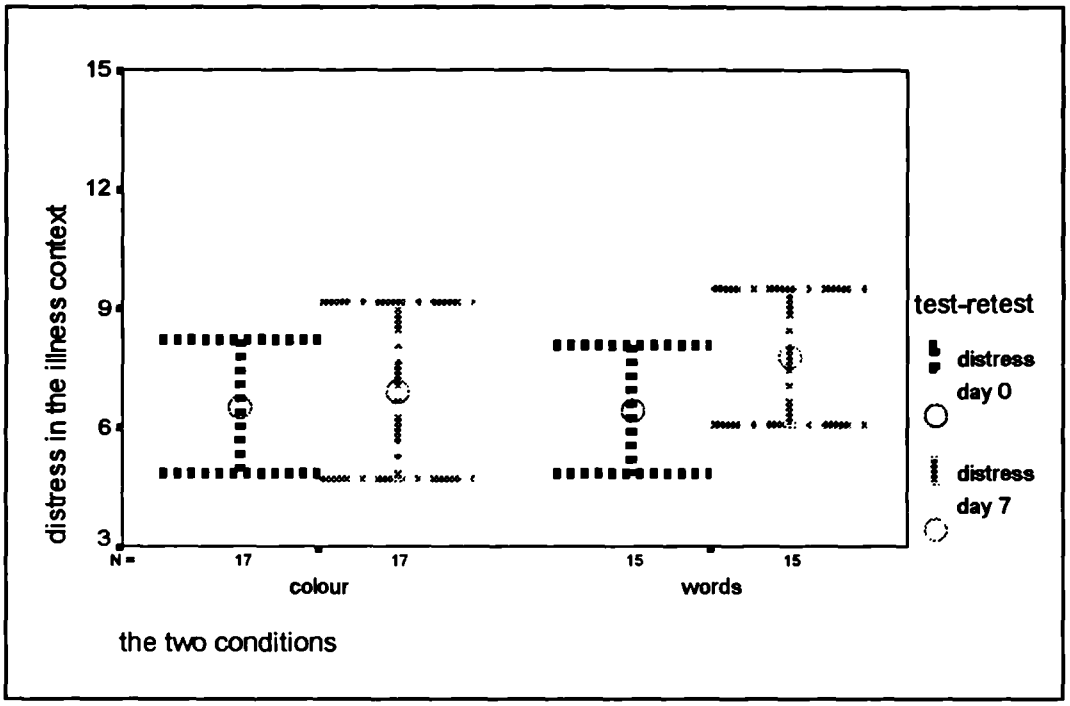


Figure 3.3 Self-reported distress: test-retest and two conditions in the illness related context (N=32)

Spearman's rank correlation was used to see if the three distress elements and total distress reported within the illness related context on the first day and one week later were associated. Significant relationships were established between the distress elements in the illness related context on day 0 and on day 7; nervous/anxious ϱ=.77, sad/unhappy ϱ=.70 and cross/angry ϱ=.76 were significant at p<.001.

Test-retest results for the self-reported distress mean scores are illustrated by Figure 3.3, the two conditions (colour coded and original words) are also represented. An excellent correlation between total distress on day 0 and day 7 in the illness related context confirms reliability (ϱ=.87, p<.001, N=32).

3.8 Kidcope: coping strategies reported to have been used by the children

This is the only part of the Kidcope Checklist where both validity and reliability have already been reported. To establish validity Spirito *et al.* (1988) compared the ten coping strategies with two standardized tests, the CSI (Tobin *et al.*, 1984) and ACOPE (Patterson & McCubbin, 1983). Reasonable agreement was reached and the results are reported in detail in Section 3.1.1.

Low test-retest correlations were reported by Spirito *et al.* when children (13 to 16 years) were asked to describe a personal stressor first, and *ten weeks* later, the same group completed Kidcope referring to *another* personal stressor. Modest to high test-retest correlations were reported in a second study where young people aged 15 to 18 completed Kidcope *three days* apart referring back to the *same* personal stressor. Results of the two studies are reported in Section 3.1.2.

These results required further investigation to test reliability. In the present study younger children (7-10 years) completed the checklist. They recalled and referred back to the *same* personal stressor after a time span of *seven days*.

3.8.1 Reliability in the common context

In the first interview children completed Kidcope by referring back to the common stressor, the scenario about an everyday-life problem, they had described. This scenario was repeated during a second one-to-one interview one week later. Results of the reliability of the ten coping strategies in the common context are measured and reported in Table 3.7.

Table 3.7 Coping strategies used by the children at day 0 and day 7 when reporting on a specific common stressor (N=32)

rank on	day 0		day 7	
day 0	strategy	frequency	strategy	frequency
1	Problem Solving	28	Problem Solving	28
2	Wishful Thinking	28	Wishful Thinking	26
3	Emotional Regulation	22	Emotion Regulation	23
4	Blaming Others	19	Blaming Others	21
5	Social Support	19	Distraction	21
6	Distraction	17	Social Support	18
7	Social Withdrawal	11	Social Withdrawal	12
8	Self-criticism	10	Self-criticism	11
9	Cognitive Restructuring	4	Cognitive Restructuring	5
10	Resignation	4	Resignation	4
	sum total	162	sum total	169

From the order in Table 3.7 it can be seen that the coping pattern stayed more or less the same from day 0 to day 7, with one 'crossover' for Distraction and Social Support. The total number of coping strategies reported to have been used by the children increased sightly from 162 to 169. Reliability for the ten coping strategies in the common context is confirmed.

Spearman's rank correlation was used to examine the total number of coping strategies (with a possible range of 0 to 10) reported to have been used by each child when dealing with a common problem on day 0 and on day 7. A significant relationship was found (ϱ=.79, p<.001, N=32).

3.8.2 Reliability in the illness related context

In the first interview children completed Kidcope by referring to the illness related stressor, the recent-illness scenario, they had described. This scenario was repeated a second time one week later. Results of the reliability of the ten coping strategies in the illness related context are measured and reported in Table 3.8.

Table 3.8 Coping strategies used by the children at day 0 and day 7 when reporting on a specific illness related stressor (N=32)

rank on	**day 0**		**day 7**	
day 0	strategy	frequency	strategy	frequency
1	Social Support	30	Social Support	32
2	Problem Solving	30	Problem Solving	29
3	Distraction	26	Distraction	25
4	Wishful Thinking	21	Wishful Thinking	21
5	Emotional Regulation	18	Resignation	18
6	Resignation	17	Emotional Regulation	14
7	Cognitive Restructuring	8	Cognitive Restructuring	8
8	Self-criticism	5	Self-criticism	8
9	Social Withdrawal	3	Blaming Others	3
10	Blaming Others	2	Social Withdrawal	1
	sum total	160	sum total	157

In the illness related context six coping strategies stayed in the same position while two pairs changed their order from day 0 to day 7: these were Emotion Regulation and Resignation, Social Withdrawal and Blaming Others (Table 3.7), the total number of coping strategies reported to have been used stayed about the same.

Spearman's rank correlation was applied to examine the total number of coping strategies reported to have been used by each child when dealing with the same illness related problem on day 0 and day 7. A weak but statistically significant relationship was found (ρ=.46, p<.01, N=32). Modest reliability for the ten coping strategies in the illness related context is confirmed.

3.8.3 Consistency: coping strategies reported on day 0 and day 7

Having confirmed the reliability of the ten coping strategies in the common and the illness related context, analyses were conducted from interviews seven days apart to compare coping strategies used by each child for the same stressor (scenario).

The kappa coefficient was calculated for each of the ten coping strategies to assess test-retest reliability for individual children between coping strategies reported to have been used for the same stressor, common and illness related on day 0 and day 7. Unlike the percentage agreement method, kappa takes into account the proportion agreement expected by chance in nominal data and was therefore the preferred method of analysis. Its value falls between +1 and -1; .75 or above shows excellent agreement, .60 to .75 moderate agreement and if z=2.32, for example, it is significant at α=.01 (Landis & Koch, 1977).

Table 3.9 Day 0 versus day 7: comparing coping strategies used by the individual child (N=32)

	COMMON		ILLNESS RELATED	
coping strategy	kappa coefficient	z score	kappa coefficient	z score
Distraction	. 62	3.61*	. 71	4.04*
Social Withdrawal	. 66	3.75*	. 48	3.16
Cognitive Restructuring	. 35	2.02	. 51	2.83*
Self-criticism	. 93	5.27*	. 52	3.09*
Blaming Others	. 93	5.29*	. 78	4.54*
Problem Solving	. 21	1.15	. 35	2.04
Emotional Regulation	. 63	3.55*	. 51	2.96*
Wishful Thinking	. 87	4.97*	. 80	4.52*
Social Support	. 74	4.19*	1	^^
Resignation	. 52	2.98*	. 69	3.88*

* statistically significant agreement at the α=.01 level

^^ all children on day 7 reported having used Social Support

Eight of the ten coping strategies in the common context show significant agreement, and seven out of the ten coping strategies in the illness related context show significant agreement (Table 3.9). It can therefore be concluded that a degree of consistency in self-reported coping had been established in a young group of children.

3.9 Kidcope: perceived helpfulness

When children reported having used a coping strategy to help them cope with a common stressor, they were asked to what extent they perceived the coping strategy to have been helpful; not at all (1), a little (2) or a lot (3), the green response sheet (Figure 3.1) was used according to condition 1 or condition 2. When a child had not used a coping strategy the helpfulness part of the Kidcope Checklist was ignored, and there was no helpfulness score.

Table 3.10 Helpfulness as perceived and reported by the children (N=32)

	COMMON				ILLNESS RELATED			
	day 0		day 7		day 0		day 7	
How much did it help?	freq	%	freq	%	freq	%	freq	%
1 not at all	57	35.5	48	28.5	41	26.0	39	24.5
2 a little	57	35.5	65	38.5	57	36.0	53	33.3
3 a lot	47	29.0	56	33.0	60	38.0	67	42.2
total number of coping strategies used	161	100	169	100	158	100	159	100

The percentage scores in Table 3.10 show that the children rated the coping strategies they used as most helpful when they referred to an illness related problem. Table 3.10 also shows that although the percentage scores are not equal between day 0 and day 7, the pattern of their perceived helpfulness has remained the same over the seven days. This result was explored in more detail and is reported below.

3.9.1 Reliability and validity in the common context

In the first interview the children completed Kidcope referring back to their specific stressor related to the common or everyday-life context. The same questions were repeated seven days later. The results of the reliability of the perceived helpfulness part and the validity of the colour coded response sheet were assessed and are presented in Table 3.11.

Table 3.11 Perceived helpfulness of coping strategies used in the two conditions in the common context on day 0 and day 7

		COMMON CONDITION 1 (n=17) frequency or percentage scores		**COMMON** CONDITION 2 (n=15) frequency or percentage scores	
How much did it help?		day 0	day 7	day 0	day 7
colour	1 not at all	34 or 41%			25 or 33%
	2 a little	27 32%			28 36%
	3 a lot	23 27%			24 31%
	strategies used	84 100%			77 100%
word	1 not at all		23 or 25%	23 or 30%	
	2 a little		37 40%	30 39%	
	3 a lot		32 35%	24 31%	
	strategies used		92 100%	77 100%	
colour-	1 not at all	16%		3%	
word	2 a little	- 8%		-3%	
	3 a lot	- 8%		0%	

Some differences were found between the children's perceived helpfulness in condition 1 and condition 2. The children who used the colour coded response sheet first (condition 1) reported more coping strategies to have been *not at all helpful* on day 0 than seven days later; the difference is 16%. The children who used the original words on day 0 have similar scores on day 7 when the colour coded response sheet was used. These results are explored further and presented in Table 3.12.

Table 3.12 The coping strategies and their perceived helpfulness in the common context (N=32)

	COMMON mean scores								
coping strategies	colour day 0	word day 0	colour day 7	word day 7	total day 0	total day 7	total colour	total word	grand mean
Distraction	1.70	1.86	1.92	1.89	1.76	1.91	1.80	1.87	1.83
Soc.Withdraw.	1.60	1.83	2.00	1.71	1.73	1.83	1.80	1.77	1.78
Cog.Restructur.	3.00	2.00	2.33	2.50	2.25	2.41	2.61	2.25	2.33
Self-criticism	1.60	1.40	1.67	1.60	1.51	1.64	1.63	1.50	1.53
Blame Others	1.30	2.00	1.70	2.00	1.63	1.86	1.50	2.00	1.75
Prob. Solving	2.33	2.31	2.44	2.08	2.32	2.29	2.36	2.20	2.30
EmotionRegul.	2.18	1.91	2.33	1.82	2.05	2.09	2.25	1.86	2.07
Wish.Thinking	1.50	1.92	1.80	1.91	1.68	1.85	1.65	1.91	1.77
Social Support	2.56	2.40	2.64	3.00	2.47	2.78	2.61	2.70	2.63
Resignation	1.00	2.00	1.50	1.00	1.25	1.25	1.25	1.50	1.25

The children reported that Social Support, *I tried to feel better by spending time with others like family and friends*, was the most helpful coping strategy when dealing with a stressor in the common context, followed by Cognitive Restructuring, *I tried*

to see the good side of things and Problem Solving, *I tried to sort out the problem by thinking of answers.*

When the total helpfulness mean scores reported on day 0 and the total helpfulness scores reported on day 7 were evaluated using the Mann-Whitney U test no significant differences were found.

These results suggest that for the first time validity for the colour coded response sheet and reliability for the helpfulness part of the Kidcope Checklist have been established in the common context.

3.9.2 Reliability and validity in the illness related context

When children reported having used a coping strategy to help them cope with an illness related stressor, they were asked to what extent they perceived it to be helpful. The same questions were repeated seven days later. The results of the reliability of the perceived helpfulness and the validity of the colour coded response sheet are assessed and presented in Table 3.13.

Table 3.13 Perceived helpfulness of coping strategies used in the two conditions in the illness related context on day 0 and day 7

		ILLNESS RELATED CONDITION 1 (n=17) frequency or percentage scores		ILLNESS RELATED CONDITION 2 (n=15) frequency or percentage scores	
How much did it help?		day 0	day 7	day 0	day 7
colour	1 not at all	20 or 24%			20 or 27%
	2 a little	26 31%			25 33%
	3 a lot	38 45%			30 40%
	strategies used	84 100%			75 100%
word	1 not at all		19 or 23%	21 or 28%	
	2 a little		28 33%	31 42%	
	3 a lot		37 44%	22 30%	
	strategies used		84 100%	74 100%	
colour-	1 not at all	1%		1%	
word	2 a little	-2%		9%	
	3 a lot	1%		-10%	

Small differences only were found between the children's perceived helpfulness in condition 1 and condition 2. The children who used the colour coded response sheet first (condition 1) have similar scores. The children who used the original words first reported more coping strategies to have been *a little helpful* and fewer children reported them to have been *a lot helpful* (10%) one week later. These results are explored further and expanded on in Table 3.14.

Table 3.14 The coping strategies and their perceived helpfulness in the illness related context (N=32)

	ILLNESS RELATED mean scores								
coping strategies	colour day 0	word day 0	colour day 7	word day 7	total day 0	total day 7	total colour	total word	grand mean
Distraction	2.40	2.36	2.43	2.18	2.38	2.32	2.42	2.27	2.35
Soc.Withdraw.	xx	1.50	xx	2.00	2.00	2.00	xx	1.75	2.00
Cog.Restructur.	3.00	2.40	3.00	2.00	2.63	2.38	3.00	2.20	2.50
Self-criticism	xx	1.00	xx	1.20	1.00	1.50	xx	1.10	1.25
Blame Others	1.00	xx	1.33	xx	1.00	1.33	1.16	xx	1.17
Prob. Solving	2.47	2.31	2.53	2.50	2.40	2.52	2.50	2.41	2.46
EmotionRegul.	1.89	1.86	1.86	2.86	1.88	2.36	1.88	2.36	2.12
Wish.Thinking	1.73	1.50	1.64	1.70	1.62	1.67	1.69	1.60	1.65
Social Support	2.77	2.54	2.77	2.53	2.67	2.66	2.77	2.54	2.66
Resignation	1.22	1.50	1.33	1.44	1.35	1.39	1.28	1.47	1.37

xx no coping strategies were used, therefore there are no perceived helpfulness mean scores to report

This group of school children found Social Support the most helpful coping strategy when dealing with an illness related stressor. Social Support was closely followed by Problem Solving and Cognitive Restructuring.

When the total helpfulness mean scores reported on day 0 and the total helpfulness scores reported on day 7 were compared using the Mann-Whitney U test, no significant differences were found. The results suggest that validity for the colour coded response sheet and reliability of the helpfulness part of the Kidcope checklist have been established in the illness related context.

3.10 School, age and sex effects

The 32 healthy children from three London primary schools completed Kidcope on two occasions, seven days apart. Seventeen boys and 15 girls with an age range of 84 to 123 months took part in this study.

No significant differences were found between *school* or *sex* in the Kidcope results (distress, coping strategies and helpfulness), nor was there a significant association between *age* and the Kidcope results. The children's feeling of distress related to the stressor they described, their way of coping with the stressor and the perceived helpfulness of the coping strategies used to help them deal with the stressor were not notably influenced by the school they went to, whether they were a boy or a girl, or if they were younger or older.

3.11 A summary of the results

The distress elements, coping strategies and helpfulness part of Kidcope (Spirito *et al.*, 1991) were considered in detail. The findings reported in this chapter show the Kidcope Checklist to be a reliable self-report instrument and one that children as young as 7 years of age are able to complete with or without the colour coded response strip.

The colour coded response strips, designed to simplify the administration of the distress elements and the helpfulness part were validated for the first time in the present study. Results of the validation of the distress element are reported in Study 3 in Section 6.6.

To answer the relevant research questions asked in the five studies, which follow and which involve children with a serious illness, it was important that the coping instrument should not only be a reliable and valid instrument but also theory driven

(relating to the transactional model of stress and coping put forward by Lazarus & Folkman, 1984) and that it should be designed with a clinical population in mind. It also had to be sufficiently brief to ensure the maintenance of children's attention when administered more than once. It was decided that Kidcope was the appropriate measure.

CHAPTER FOUR
A METHODOLOGICAL OVERVIEW
RELATED TO THE HOSPITAL BASED STUDIES

The principal aim of the five hospital based studies was to find out more about coping by seriously ill children. All the children who took part suffered from a life-threatening illness.

Interviews which included completing Kidcope, the observations of the children's distress during a blood test (OSBD) and their coping behaviour (taking an active interest or lacking interest) will be referred to as the *core of coping*. These results are reported in Chapters 5 and 6. Having focused on the core of coping, a broader view of coping will be taken to explore more general questions, such as the association between coping and individual differences of the children and coping and their families' influence on it.

Individual differences, including the children's perceived feeling of competence and self-worth, their age, whether they as boys or girls show differences or similarities in coping and the time since the disease was first diagnosed, all contribute to the picture of how children cope with a serious illness. The results which focus on these differences are presented in Chapter 7. *Parental influence* as well as the *social climate of the family* and their possible influence on the children's way of coping will be evaluated and discussed in Chapters 8 and 9 respectively.

4.1 The sample

A total of 58 children in long term patient care took part in this study. Fifty three of them completed every aspects of the data collection. Five children failed to complete the studies for the following reasons: one girl went back to Cornwall,

one girl was transferred to a Bristol hospital for a bone marrow transplant, two boys were moved to other London hospitals and one teenage girl died suddenly.

The data were collected from January 1993 to November 1994. The children who make up the five studies were consecutive referrals. They were recruited without regard to the phase of their illness or to the stage in their treatment. The researcher communicated regularly with the medical team and the recruitment of subjects was dependent on the number of children being admitted to the hospital. When asked if they would take part in the study, 58 out of 60 families (97%) responded positively - a sufficient number to provide a representative sample. Two families refused due to "I don't have enough time" and "We are going to be transferred to another hospital as soon as possible." The children were patients in one of two London teaching hospitals and had either *leukaemia* (acute lymphoblastic leukaemia ALL or acute myeloid leukaemia AML) or *aplastic anaemia.* Both diseases are blood related showing no visible physical effects such as scars, lumps or amputations and both are potentially life threatening. Both groups were treated by the same medical teams.

Leukaemia, meaning 'white blood', is a global name for malignant tumours arising from the developing blood cells. Such tumours fill the marrow with abnormal cells which then enter the circulation. Most leukaemias start in the bone marrow but some start in the lymphatic system. In all instances the marrow, by definition, ends up being the main site of the disease. Leukaemia is treated with radiotherapy and/or cytotoxic drugs and in some cases with a bone marrow transplant. The chances of developing leukaemia in childhood are rare. In the UK during the first 15 years of life they are less than 1:1500 (Lilleyman, 1994).

The word anaemia means literally 'lack of blood', and aplastic anaemia is a serious blood disorder in which all cellular elements of blood and bone marrow are reduced in number due to the failure of blood cell precursors to respond. There are various causes including reaction to toxic drugs. Treatment includes bone marrow transplant and cytotoxic drugs.

Table 4.1 The composition of the sample

		aplastic anaemia		leukaemia		
hospital		boys	girls	boys	girls	total
St George's		3	5	1	3	12
St Bartholomew's				27	14	41
total		3	5	28	17	53
age in months:	range	58-165	122-172	84-194	85-193	84-194
	mean	113	143	125	138	130
^experience in months:	range	4-58	2-33	2-67	2-66	2-67
	mean	26	17	29	36	27

^experience = time since the child was first diagnosed having aplastic anaemia or leukaemia

The children were aged from 7 to 16 years. The age level of seven corresponds to the minimum age of the adjusted Kidcope Checklist (see Study 1) and the age level of 16 years corresponded to the upper age limit of children in the paediatric wards. Twelve (23%) of the subjects were recruited from St George's and 41 (77%) from St Bartholomew's hospital. St George's hospital has a specialised unit for children with aplastic anaemia and leukaemia and St Bartholomew's hospital for children with leukaemia. These hospitals admit children from local areas as well as further afield. The children are of a mixed ethnic and social background. Table 4.2 illustrates the family composition and the position the child holds within it. The *sex* distribution, 31 boys (58%) and 22 girls (42%) is in accordance with the population of these patients. There is an imbalance between the sexes with a slight excess of boys diagnosed with leukaemia. Boys comprise 55 to 60 percent of all cases (Eden, 1994).

Similarities or differences between the children with aplastic anaemia and leukaemia did not form part of the research questions. However, these two groups were compared on all measures used in this thesis and no significant differences were found. They were therefore treated as one group throughout.

The number of months of *experience*, or the time since the disease was first diagnosed, ranged from 2 to 67 months. The disparity is mainly due to the nature of the patient group and their illness. Some of the children were first-time patients while others were known to have enjoyed a long remission period. During the remission period they attended regular hospital visits most of which were routine, but in some cases involved related medical complications and infections of various kinds. Thirteen children in this group had relapsed after a long period and were obliged to start the treatment all over again.

Table 4.2 The family structure and the number of children within it

family structure	one child	two children	three children	> three children	total number of children
single parent family	2	5	3	1	11 21%
two parent family	2	18	14	8	42 79%
total number of children	4 8%	23 43%	17 32%	9 17%	53 100%

The number of children per family ranged from one to six, with a median of two children. Eleven of the children (21%) who took part come from single parent families where the parent is the mother, and 42 children (79%) come from two-parent families. The majority (43%) of the children have one brother or sister and 29 (55%) are first born.

Similarities and differences in family structure and their possible influence on children's coping will be explored together with parental coping and the social climate of the family in Chapters 8 and 9.

4.1.1 Gaining access

The researcher had no previous experience of working on a hospital ward and gaining access to children with a life threatening illness was a challenging task. Advice offered by the medical team was taken and a volunteer post as a play leader on a paediatric ward was sought and permission granted. For six months, while the research proposal was written, presented, and accepted by the Ethics Committee, the researcher worked on Snow Ward in St George's hospital. This work formed an essential part of the research as familiarisation with the routine and atmosphere of a hospital ward helped to minimize the intrusion with the medical team as well as with the young patients and their families. It also made their recruitment easier.

Approval of the research design and procedure was finally secured from the Wandsworth Health Authority Ethics Committee and later from the Bart's NHS Group Trust Headquarters Research Ethics Committee. For application and correspondence concerning the research proposal see the appendix. Once access was granted, available children and their parents were asked if they would be willing to take part in the study. One of the parents and children aged 12 or older signed the consent form.

A clear explanation of the procedure was given to the children, and both adults and patients were told that they could refuse or postpone a session at any time, according to their circumstances. As children with leukaemia and aplastic anaemia are a vulnerable group, this turned out to be an important condition. Chemotherapy makes many of them feel ill and tired at unpredictable times so that pre-arranged sessions were changed whenever necessary to suit the child's wellbeing. Patients and their families were very co-operative throughout the study.

The 53 children who completed all five studies are treated as one group unless stated otherwise. Results on testing for subgroups are reported in Study 4, Chapter 7.

4.2 A brief overview of the procedures of all five hospital based studies

Once written consent was obtained, a comprehensive information sheet about each child was completed with the help of the parents. An example of the information sheet appears in the appendix. Using self-report, observation and interview methods, the collection of data from each child required five separate sessions. Using one-to-one self-report method, collecting the data from the parents took place during three sessions. Two of these sessions were with the main caregiver and one with the other caregiver from the two parent families. The instruments are included in Appendices IV-IX).

4.2.1 Data collection took place as follows:

Session 1

Preliminary contact with the young patient and the family took place as early as possible while the child was settling in to the hospital routine. The researcher spent this first period with the patient playing age-appropriate games or watching videos, using the opportunity to get to know each other.

Session 2

The Susan Harter Perception Profile for Children (1985) questionnaire was administered. This test assesses the child's perception of *competence* and *self-worth* and details about the checklist and results are reported in Chapter 7.

Session 3

The child's response to a medical procedure was observed. Immediately before, during and after a routine blood test, the child's distress behaviour was systematically observed and recorded using the Observational Scale of Behaviour Distress (Jay & Elliott, 1986). The eight *OSBD behaviour* categories, *parental presence* or *absence* and the child's *coping behaviour* (active/lack of interest in the medical procedure) were recorded on a checklist. Details about the observation schedule and results are reported in Chapter 6.

Session 4

With the help of the researcher, the patient completed the Kidcope self-report checklist (Spirito *et al.*, 1988, 1991; Pretzlik & Hindley,

1993) and three particular problems were described. A stressor in the *common* and in an *illness related* context and the *blood test* observed during Session 3 were the focus of attention. The children responded to each problem and talked about how they had felt answering the Kidcope questions. Details about the Kidcope Checklist and results are reported in Chapter 5.

Session 5

A semi-structured interview related to the patient's *understanding* of his or her illness was carried out. The conversation was recorded and later transcribed. Details and results are not included in the thesis, but will be analysed and reported on at a later stage.

Sessions 6 and 7

This session explored the *adults' coping pattern* used during their child's illness. The CHIP (Coping Health Inventory for Parents), an assessment of parental coping patterns caring for chronically ill children (McCubbin, McCubbin, Patterson, Cauble, Wilson & Warnick, 1983; Eiser & Havermans, 1992), was completed by all parents independently. Details of the questionnaire and results are reported in Chapter 7.

Session 8

The main caregivers completed the FES Family Environment Scale (Moos & Moos, 1986), a well established instrument. This measure looks at the social climate of the family, the details and results of which are reported on in Chapter 9.

Pilot work relating to the above mentioned procedure is reported below in Section 4.3. The method and procedure of the various aspects of this study are reported in detail in the first part in each of the next five chapters.

4.3 Pilot work

It was decided to approach children from the community and out-patients at St George's hospital to test and become familiar with the procedures before collecting data from the main sample. Seriously ill children need be protected as much as possible and access is difficult to obtain. The long-term patients were only asked to take part in the main studies once the preliminary studies were completed, the

research schedule had been fully tested and the researcher was familiar with medical treatments, hospital routines and the medical team.

4.3.1 Pilot work on Kidcope for Older Children

Kidcope for Younger Children was the instrument used in Study 1 which was reported in Chapter 3. During a small pilot study involving six children from the community (14-16 years; 2 boys and 4 girls) it was found that the 4 point Likert-type scale on the Kidcope for Older Children was confusing them.

The questionnaire for Older Children has a graded frequency scale in answer to each item.

> For example:
>
> "I realised I brought the problem on myself and blamed myself for causing it" is answered by: "How often did you do this?"
>
> *'Not at all', 'Sometimes', 'A lot of the time'* or *'Almost all the time'.*

As discussed in Chapter 3 the children were asked to describe a specific stressor in a specific situation. When referring to the stressors and answering the coping questions it was found that the simple answer of *yes* or *no*, as in the version for Younger Children, was a clearer and more accurate way of reporting and scoring the number of coping strategies.

It was thought important to keep the answers clear and at the same time maintain the definition of coping by Lazarus and Folkman (1984) on which Kidcope and its procedure is based. Children refer to a specific stressor in a specific situation. By changing the answers to the coping strategies from a 4 point Likert-type scale to a yes or no answer a compromise was necessary - the ordinal data was converted into nominal data.

Although the adjustment of the questionnaire for Older Children makes the two versions of Kidcope comparable, it becomes less easy to compare directly the results of the present studies with those of Spirito *et al.* (1988, 1991). In their most recent work, however, Spirito *et al.* (1995) reported the same changes.

4.3.2 A study using Kidcope for Younger Children in the community

A cross-sectional design was used to explore developmental trends in children's reported distress resulting from individual problems, the frequency of coping strategies used and the degree of the perceived helpfulness of those coping strategies.

Thirty two children from 5 to 10 years of age took part in the study. Each child recalled a common and an illness related problem and rated the degree of distress they experienced. A colour coded response sheet was developed to help the children (reported in Chapter 3, also see Figure 3.1) and Kidcope was completed relating the answers to each child's specific scenario. The coping items reported to have been used (yes or no) were also rated by the children according to how helpful he or she perceived them to be.

A significant age effect was found; older children (8-10 years) used more coping strategies than the younger ones. Results also indicate that although younger children (5-7 years) used fewer coping strategies they reported them to be more helpful than the older group. Younger children with high distress scores reported a greater frequency score. In spite of the small sample used in this pilot study, the main purpose was achieved. Kidcope was found to be easy to administer, and appeared to provide a complex assessment appropriate for use in conjunction with other instruments and other research methods (e.g. direct observation, semi-structured or open-ended interview). This healthy group of children managed the self-report checklist well and used the colour strips with success (Pretzlik & Hindley, 1993).

4.3.3 Pilot work on the Observation Scale of Behaviour Distress

To ensure the researcher would be comfortable and 'fluent' with all the research instruments before starting the data collection for the main studies, pilot work with the observation method was also required. For two days, during routine blood tests, observations were made using the OSBD categories to record distress related behaviour. The observations took place in the out-patient department in a London teaching hospital, permission having been given by the paediatric consultant. The interrater reliabilities of the OSBD categories and the coping behaviours (taking an active/lack of interest in the medical procedure) are reported in Section 6.3.

Twelve children, (between 18 months and 9 years old and with a mixed medical history) were observed. The researcher placed herself discreetly in the corner of the consulting room. A bleeper defining 15 second intervals was used and the behaviours were recorded on a prepared checklist which included the *eight distress behaviour categories*, the *two coping behaviours* and *parental presence* or *absence*. A satisfactory and smooth use of these instruments was achieved.

4.3.4 Pilot work on the Self-Perception Profile for Children questionnaire

The purpose of this small scale study was to make an informed choice as to which of the questionnaires devised by Susan Harter were appropriate to use in Study 4. Three versions exist: The Pictorial Scale of Perceived Acceptance for Young Children (1981) for children up to the age of eight, The Self-Perception Profile for Children (1985) for children from 8 to 16 years and The Self-Perception Profile for Adolescents (1988) for young people from 14 years.

4.3.4.1 The Self-Perception Profile for Children

Six children from the community (7-9 years; 3 boys, 3 girls) completed the Self-Perception Profile for Children questionnaire. The 36 items were read out by the researcher during one-to-one interviews. The children managed to complete the questions without difficulty.

An older group of six adolescents from the community (14-16 years; 3 boys, 3 girls) completed both the Self-Perception Profile for Children *and* the Self-Perception Profile for Adolescents. It made no difference to these six people which of the two instruments they used.

In spite of the age range from 7 to 16 years a decision was taken to administer the Self-Perception for Children questionnaire to all children in the main study.

4.4 Analysing the data

Both inter- and intra-individual analysis were undertaken in this study. Intra-individual analyses enable the investigation of different kinds of stressful situations in *individual* children, as well as the comparison of interview and observation data. It compares the coping strategies within and across three contexts (three stress scenarios) and the distress and coping behaviours used during a medical procedure. The inter-individual analyses, however, compare *groups* of children in terms of coping (types of stressors) and distress (coping behaviour) data collected through interviews and observations.

While keeping the child at the centre of all research questions, the first and main part of the result section focuses on the context in which coping with a problem took place; behavioural observations are also reported and related to self-reported distress and coping. Individual differences of the child form the basis of the next part of the

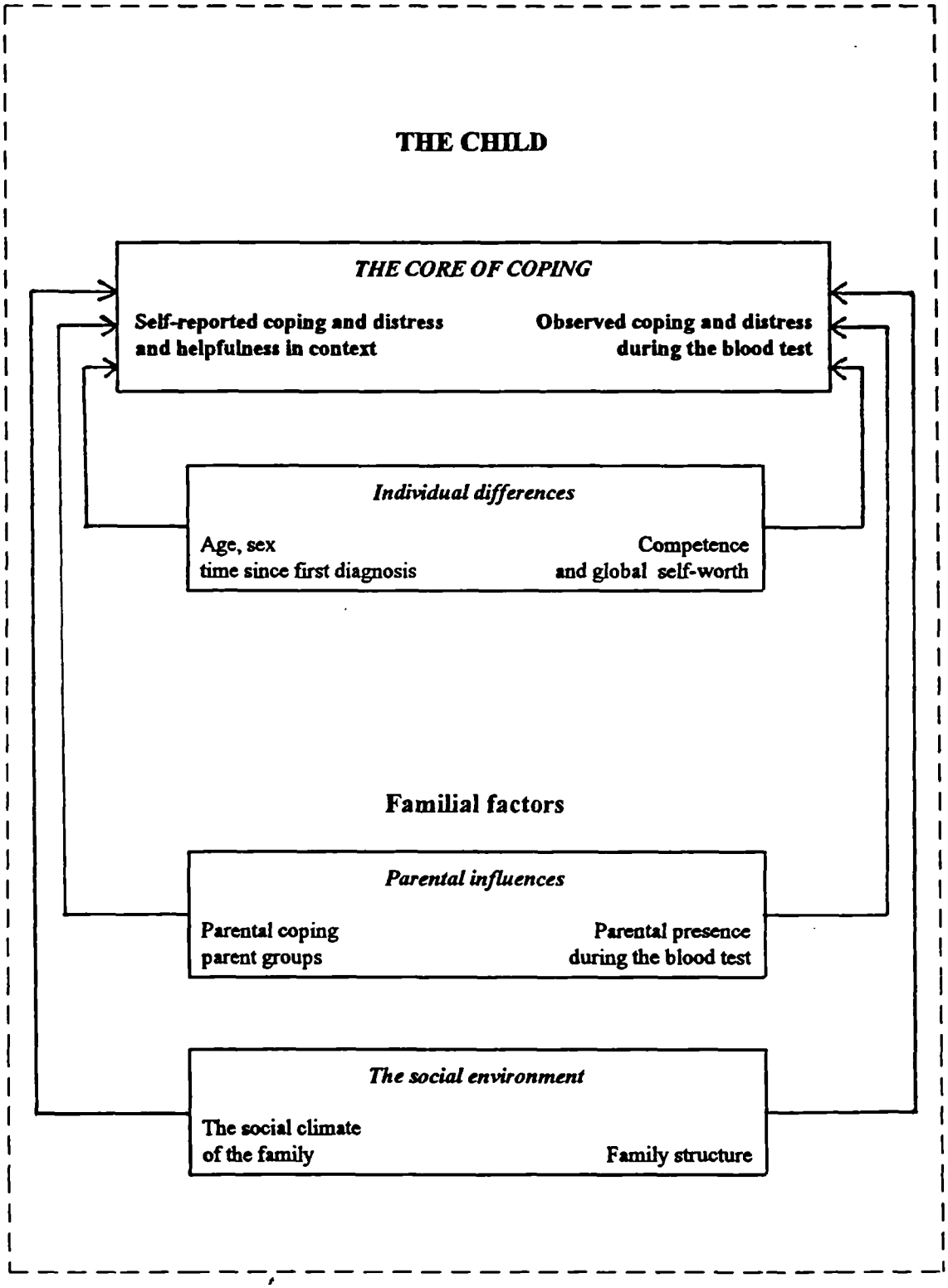


Figure 4.1 The conceptual model guiding this thesis

analysis. Parental coping is considered and finally the family, its formation and social climate is focused on and compared with the children's way of coping.

The conceptual model guiding this thesis is represented by Figure 4.1.

4.4.1 The core of coping

Chapters 5 and 6 explore both the results of the self-reported coping and distress described in the children's interviews and the distress and coping behaviours observed during a medical procedure. The results from the Kidcope Checklist, the Observation Scale of Behaviour Distress (OSBD) and the coping behaviour (devised for this study) make up *the core of coping* in this thesis.

4.4.2 Individual differences and their possible influence on coping

In Study 4 the *individual differences* of the children are made up of four parts: the results of the Perception Profile for Children Scale (the patients' perceived competence and self-worth); being older or younger; being a boy or a girl; and the time since the illness was first diagnosed. These results were evaluated as were the possible influences of individual differences on the way children cope and will be reported on and discussed in Chapter 7.

4.4.3 The parents and the family and their possible influence on their children's coping

Parental coping patterns measured by the Coping Health Inventory for Parents, parental presence or absence during the blood test (Study 5), family formation, and the social climate of the family (Family Environment Scale) and the way children cope with the illness (Study 6) will be reported on and discussed in Chapters 8 and 9.

4.4.4 The understanding part of the data

Permission was given by both ethics committees (St George and St Bartholomew's hospital) for the semi-structured one-to-one interviews of *children's understanding of illness* to go ahead. The data were collected from 53 children and the recorded interviews transcribed. However, due to time limitations and the structure of the thesis it was decided not to include them. The data will be analysed at a future date, using the NUDIST computer package designed to support researchers looking at non-numerical data in qualitative analysis (also see Appendix IX).

4.5 A final comment

The hospital based studies will be reported in the next five chapters. They look at the way children with aplastic anaemia and leukaemia cope. It would be interesting to compare this group with another, diabetics for example, but that is not a question to be address here. This thesis takes a different direction in that it is not the disease itself but the patterns of association within this one group of children that is studied in depth.

Coping of a fairly homogenous patient group is explored intensively using a variety of research methods. The instruments for studying the children spanned from a structured observation using the OSBD during a real-live specific medical procedure, to a questionnaire about children's perception of competence and self-worth using the Self-Perception Profile for Children, and a partly structured interview using the Kidcope Checklist. The instruments to study the families included two different self-report questionnaires - the CHIP and the FES - as well as information about the family given by the parents. The reported findings will contribute to our understanding of children's coping processes. By attempting to answer the research questions presented in the following chapters it is hoped to broaden the conceptual framework and create a fuller picture of how children with a serious illness cope.

CHAPTER FIVE
SELF-REPORTED COPING AND SELF-REPORTED DISTRESS
Study 2

The primary research questions were derived from Folkman and Lazarus' (1984) definition of coping, and it was this definition which forms the framework of the present study. Coping is concerned with change and looking at the process of coping involves looking at what is *actually* happening not what *usually* happens or is believed to happen.

In addition to coping with illness related stressors, children with a serious illness must deal simultaneously with the demands of everyday stressors, both minor and major. The exposure to multiple stressors, that is to say everyday-life and illness related stressors, places extraordinary demands on children who suffer from leukaemia or aplastic anaemia. Empirical work on how they perceive their stressors and the related coping strategies can identify whether coping strategies are specific to particular types of stressor or whether generalisations can be made across stressful situations. Such information would help with the design of psychosocial interventions to enhance the coping efforts of ill children.

Results from the one-to-one interviews (Kidcope) reported in this chapter, and the observations of children's distress (OSBD) and coping behaviour (showing an active interest or showing no interest in the blood test) reported in Chapter 6 make up what is referred to in this thesis as *the core of coping.*

Research questions:

Is there consistency in coping *across* the three contexts (common, illness related, blood test)?

What is the relationship between the number of coping *strategies* children use and their perceived *helpfulness* within the three contexts?

Do the *type of stressors* selected by the children vary within the common or illness related context?

Is there consistency in coping *within* the common or illness related context?

Is there consistency in self-reported distress *across* the three contexts (common, illness related, blood test)?

What is the relationship between the number of coping *strategies* children use and their self-reported *distress* (feeling nervous/anxious; sad/unhappy; cross/angry) within the three contexts?

All the results in this chapter are based on the Kidcope Checklist.

METHOD

5.1 Assessing coping in seriously ill children

The two Kidcope Checklists used in this study are similar and follow the same basic structure. Kidcope for Older Children (Spirito *et al.*, 1988) was used for 13-16 year olds. The scale for the Younger Children (Spirito *et al.*, 1991) was derived from the scale for Older Children. The adaptation of the instrument to a younger British sample as well as its reliability and validity were reported in Chapter 3.

The decision as to which version of Kidcope should be used was a function of the children's ages. Coping in children and adolescents across situations (contexts) is assessed by completing Kidcope more than once.

5.1.1 Rationale for using the Kidcope

The Kidcope Checklist is the only coping questionnaire that has been standardised specifically for chronically ill children and is based on the adult model of coping put forward by Lazarus and Folkman (1984). The child is asked to generate and recall a stressful situation rather than respond to a situation that is selected by someone else.

It measures coping satisfactorily and does not take long to administer. Fifteen items make up the ten coping strategies. The short checklist is concise, easy to manage and therefore useful in a clinical setting. For research purposes it allows repeated administration, its brevity is such that the child's cooperation and concentration are maintained throughout the interview. Children's coping with different stressors within a context and across different contexts can be assessed and compared.

5.2 Categorisation and reliability of the children's self-reported stressors

The scenarios, or what throughout the result sections are referred to as stressors, were categorised by the researcher and the results are reported in Section 5.8. Interrater reliability for the categorisation of the scenarios chosen by the children in the common and the illness related context was tested by two raters: Rater A (a psychologist) and Rater B (another qualified psychologist). Fourteen scenarios were picked at random from each of the two contexts and categorised by the raters according to the *content*. Reliability was tested using simple percentage agreement. For the Kidcope *common* problem this was 93%. Agreement was reached in thirteen cases, the exception was discussed and later agreed on. For the Kidcope *illness* related problem, inter-rater agreement on content was 86%. There was agreement in twelve cases while the other two were discussed and agreement was reached. For examples and results of the content analysis see Sections 5.8.1 and 5.8.2.

5.3 The Kidcope Checklist: the procedure

Kidcope was administered to all 53 children by the same researcher during a one-to-one interview. All the children were patients in one of two London hospitals. The checklist was completed during one session. The interview took place, after observing the blood test (reported in Chapter 6), in a quiet corner of the hospital, either on the ward or in one of the rooms in the out-patient department. The absence of parents and medical staff during the interviews avoided the possible influence of social desirability on the children's responses.

The instructions and the coping items were read out to the patient and the checklist was completed in an interactive style. Those items that a child did not understand were discussed and explained. The children were given a choice of doing the writing and ticking the boxes themselves or having the researcher do it. Each of the response choices was read out to ensure clear understanding of possible answers.

Details of the Kidcope Checklist were presented and discussed in Chapter 3 and an example of the instrument are given in the appendix.

5.3.1 The scenario: describing a stressor

Prior to the completion of each checklist the child was asked to describe a *personal stressor* in relation to one of the three contexts.

The three contexts were:

(A) a *common* or everyday stressor,

(B) an *illness related* stressor and

(C) the *bloodtest* which had been observed by the researcher

These contexts were the same for all the children but the sequence, in which they were presented, was changed. Throughout the data collection the alternate sequence of ABC, ACB, BAC, BCA, CAB and CBA was used to avoid an order effect. If the

child identified several problems within one context he or she was asked to select the one uppermost in his or her mind. Examples of problem scenarios (stressors) are give in Tables 5.8 and 5.10. Each stressor described was recorded by the researcher, using the children's own words, in the space provided. Older children often preferred to do the writing themselves. Kidcope was answered throughout in respect to the personal stressor.

Before any questions were asked about a scenario it was important to make clear that the checklist elements (distress, coping strategies and helpfulness) were to be completed with reference to the particular stressor described. Reminders about the stressor specified by the child were provided throughout the interview. When administering Kidcope it is crucial to remember that coping is measured using a specific stressor in a specific situation at a specific time.

5.3.2 Self-reported distress

Next, the child rated the amount of *distress* his or her reported stressor had caused. This was done on a 5 point Likert-type scale and the colour coded response sheet (Figure 3.1) was used to help children report on the three distress elements which make up the distress score for each of the three contexts.

Did that time (related to the described scenario) *make you feel*:

a) *nervous* or *anxious*? **(orange)**

b) *sad* or *unhappy*? **(blue)**

c) *cross* or *angry*? **(red)**

The degree of distress for each element was rated as:

not at all (1); *a little* (2); *somewhat* (3); *a lot* (4); *very much* (5).

The scores of these three distress elements (nervous/anxious, sad/unhappy, cross/angry) were added to create the *self-reported distress score* with a possible range of 3 to 15 for each context.

5.3.3 The coping strategies and their perceived helpfulness

The 15 items which make up the 10 coping strategies which form the second part of the Kidcope checklist were reported in Table 4.1 illustrates.

The 15 items were responded to as:

Did you ...? *Yes* (1) or *No* (0).

There are three possible responses on the *helpfulness* scale:

How much did it help? *not at all* (1); *a little* (2); *a lot* (3).

To make answers visual and therefore clearer to the children the **green** colour strip was applied (Section 3.3). The questions on the helpfulness scale were answered only when a coping strategy was reported to have been used.

When the helpfulness response was missing it was coded as missing and not as a zero score. This resulted in fewer helpfulness scores than coping strategies. That is to say that when a child failed to use a coping item (Table 3.1) the *How much did it help?* question was ignored. For those coping strategies that have two items, only one of the answers was scored. The answer scored was the one perceived to be most helpful by the child.

The Older Children's version was scored in accordance with the Younger Children's version (Section 4.3.1).

5.3.4 A final comment about the procedure

Overall it was found that the children enjoyed the interview, and liked describing a scenario (a specific stressor) related to them and their situation. For a child with a serious illness the Kidcope coping items which make up the coping strategies were found to be suitable and allowed the patients attention to be held to the end of the interview. This was true for the younger and the older children, all of whom were willing and able to complete the checklist three times during one interview session.

RESULTS

In this second part of Chapter 5 results from Study 2 are presented and discussed. The way in which the children coped in three different contexts and their self-reported distress are analysed and reported. These results combined with the results of the coping behaviour and the distress behaviour reported in Chapter 6 form the core of coping.

Findings from the Kidcope Checklist are presented in Sections 5.5 and 5.6 where both the number of coping strategies used and their perceived helpfulness are explored and looked at *across* the three contexts: common, illness related and blood test. In Section 5.7 coping strategies used by the individual child are compared across the common and the illness related context. Then follows the content analysis of the children's scenarios (Section 5.8) for each of the personal stressors (common and illness related). Next, differences and similarities in coping *within* a context are sought (Section 5.9). And finally, in Section 5.10, results from the distress part of the Kidcope Checklist are reported.

Statistical methods for Normally distributed as well as distribution free data were used to analyse the data. Details and rationale as to the choice of analysis will be addressed in each section as appropriate.

5.4 The spontaneous process of coping: a theoretical 'reminder'

Coping is a process and refers to what the individual actually thinks or does within a given situation. Changes take place as these thoughts and actions unfold. This definition of coping is context dependent. Thus, coping is determined not only by personal qualities but by the individual's assessment of the demands of the particular situation or stressor. And lastly, coping is defined without immediate reference to its outcome. It refers to efforts made to manage a situation, not to the 'success' or the

'failure' of the efforts. Coping, therefore, is concerned with process and change. Exploring the process of coping involves looking at what is actually happening across two or more contexts as well as within a context, and not what might happen or what 'usually' happens.

5.5 Describing differences and similarities between coping strategies used and their helpfulness

Kidcope is made up of 10 coping strategies and the 53 children were asked which of these strategies they used. The mean scores of their responses across the three contexts are summarised in Figure 5.1. The children answered with a *yes* or *no* whether they had used a coping item to help them with the specific stressor they had described. Therefore, the possible response range on this measure was 0 to 10 for each of the three contexts. The content of the self-selected stressors reported within the common and the illness related context is categorised and discussed in Section 6.8.

These responses are not Normally distributed and consequently the Friedman two-way analysis of variance by rank (for ordinal data and more than two related samples) was applied to look for contextual differences. Significant differences were found between the three contexts ($\chi^2(2)=22.79$, $p<.001$) and inspection showed (Figure 5.1) that children used considerably more coping strategies when dealing with a common and illness related stressor than for the blood test.

These differences may be purely contextual or they may partly result from the methodology used in this section of the study. The children themselves reported a wide variety of stressors that had troubled them personally in both the common and the illness related context. On the other hand, the blood test scenario was not chosen by the children, it was suggested to them by the researcher. Every child underwent this specific medical procedure, which had been observed earlier and recorded by the researcher. It may be that not all the children found the blood test stressful, and those

that did found it less stressful than the chosen stressors in the common or illness related context.

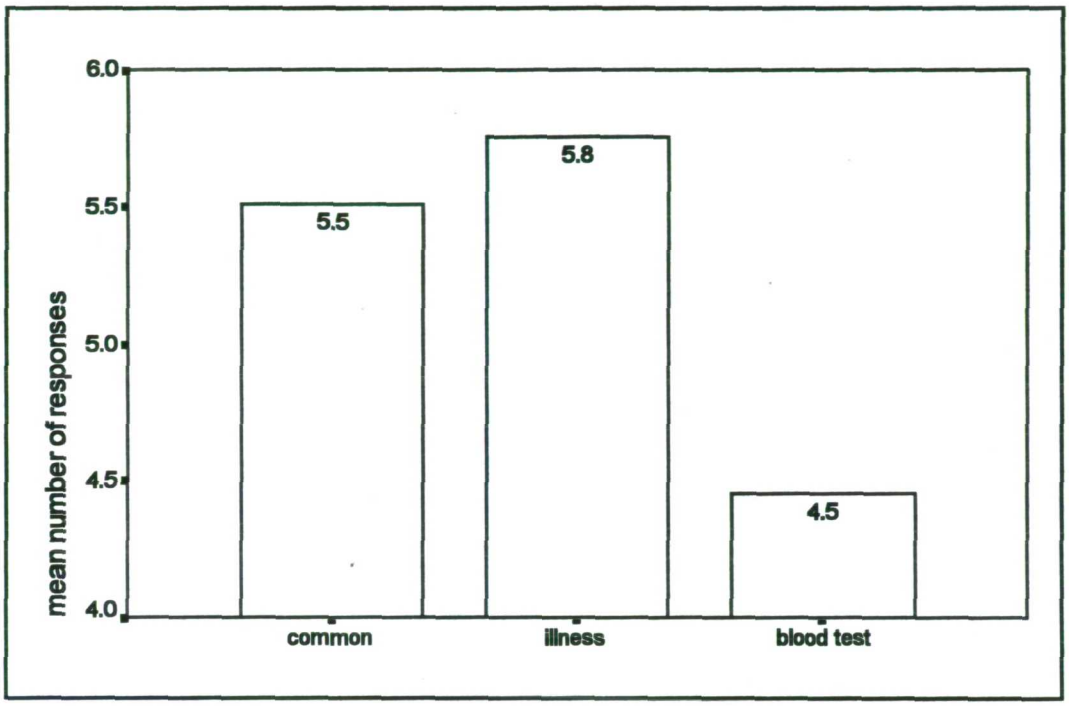


Figure 5.1 The three contexts: the total number of coping strategies used (N=53)

Once a child reported yes to having used a specific coping item, he or she was asked if this way of coping was perceived to be helpful, and if so how helpful (Tables 5.2 and 5.3). The coping strategies and their frequency are discussed in Section 5.5.1, and the perceived helpfulness in Section 5.5.2.

5.5.1 The coping strategies

Figure 5.1 illustrates the mean of the total number of coping strategies used across the three contexts. Having looked at the *total* number of coping strategies used across these contexts the *kinds* of coping strategies the children used within as well

as across the contexts are explored. The total number of coping strategies (the sum responses) used for the common problem, the illness related problem and the blood test are ranked and presented in Table 5.1. The results show differences and similarities between the kind of coping strategies reported to have been used by the children when dealing with stressors in the three contexts.

Table 5.1 Coping strategies reported by the children within each of the three contexts (N=53)

	COMMON		ILLNESS		BLOOD TEST	
rank	strategy	freq	strategy	freq	strategy	freq
1	Wishful Thinking	44	Wishful Thinking	47	Cognitive Restruct.	42
2	Emotion Regulat.	38	Distraction	45	Distraction	38
3	Problem Solving	36	Social Support	41	Wishful Thinking	33
4	Social Support	36	Emotion Regulat	39	Resignation	30
5	Distraction	33	Cognitive Restruct.	37	Emotion Regulat.	28
6	Blaming Others	27	Resignation	30	Problem Solving	23
7	Social Withdrawal	25	Problem Solving	29	Social Support	19
8	Cognitive Restruct.	23	Social Withdrawal	25	Social Withdrawal	15
9	Resignation	19	Blaming Others	9	Blaming Others	6
10	Self-criticism	11	Self-criticism	3	Self-criticism	2
	sum total	292	sum total	305	sum total	236

Spearman's rank correlation was used for all three possible pairings to see if the coping strategies used in one were used in the other. An association was found between the illness related context and the blood test and the kind of coping strategies used (ϱ=.75, p=.012, N=10). There was also an association between the everyday context and the illness related context (ϱ=.72, p=.018, N=10). However,

no significant relationship was found between the everyday context and the blood test (ϱ=.24, p=.498, N=10). It can be argued that the illness related stressor and the blood test are more likely to be comparable than an everyday stressor and the blood test i.e. the nature of the stressor should be considered. These results will be explored further in Section 5.9.

Examples from Table 5.1 illustrate some of the differences:

Cognitive Restructuring, 'trying to see the good side of things', was ranked 1 in the blood test context, but 5 in the illness related context and only 8 in the common context.

Resignation 'do nothing because the problem could not be sorted out anyway', was ranked 4 in the blood test context, but 6 in the illness related and only 9 in the common context.

Problem Solving, 'trying to sort out the problem by doing something or talking to someone about it', was ranked 3 in the common context, 6 in the blood test context and 7 in the illness related context.

Distraction, 'trying to do something like play or watch the telly' was ranked 2 in both the blood test and the illness related context, and 5 in the common context.

These children not only used a variety of coping strategies according to their stressor within a context but they also varied the coping strategy used across contexts, reflecting part of Lazarus and Folkman's (1984) definition of coping.

5.5.2 Perceived helpfulness

Only coping strategies reported to have been used by the children were assigned a *helpfulness* score, which means that the number of children responding to each

coping strategy varies. The extent to which coping strategies used were perceived to be helpful across the three contexts is shown in Table 5.2. The range is 1-3 for each coping strategy used. The question *How much did it* (a specific coping item) *help*? was answered by *not at all* (1), *a little* (2) or *a lot* (3).

The Friedman two-way analysis of variance for a related sample and ordinal data was applied to the three overall mean scores. Significant differences were found between the three contexts and the perceived helpfulness ($\chi^2(2)=22.79, p<.001$).

Table 5.2 Perceived helpfulness of coping strategies used across and within the three contexts (N=53)

	COMMON		ILLNESS		BLOOD TEST	
'How much did it help?'	freq	%	freq	%	freq	%
1 'not at all'	55	19	55	18	33	14
2 'a little'	117	40	138	46	91	39
3 'a lot'	120	41	111	36	112	47
total number of coping strategies used	292	100	305	100	236	100

Inspection of the percentage scores (Table 5.2) shows that the children rated their coping strategies as most helpful when talking about the blood test, less helpful when referring to the illness related stressor and least helpful when talking about an everyday stressor. This result of how helpful the children perceived the coping strategies to be is a mirror image of the number of coping strategies used in the three contexts illustrated by Figure 5.1. The children used the least number of coping strategies for the blood test, the stressor suggested the researchers. Yet, the coping

strategies they did use were perceived as helpful, more helpful than the ones used for the two specific personal stressors. This result is expanded on in Table 5.3.

The rank order of the perceived helpfulness mean scores are presented in Table 5.3. The children's *helpfulness* scores are directly related to the coping strategies they used (Table 5.2). These mean scores are calculated as the perceived helpfulness divided by the number of strategies used.

Table 5.3 Perceived helpfulness within each of the three contexts (N=53)

	COMMON		**ILLNESS**		**BLOOD TEST**	
rank	strategy	mean	strategy	mean	strategy	mean
1	Cognitive Restruct	2.48	Social support	2.59	Emotion Regulat.	2.61
2	Social Support	2.47	Problem Solving	2.31	Resignation	2.47
3	Distraction	2.32	Emotion Regulat.	2.26	Social Support	2.45
4	Emotion Regulat.	2.29	Distraction	2.24	Distraction	2.39
5	Problem Solving	2.22	Cognitive Restruct	2.19	Cognitive Restruct	2.36
6	Blaming Others	2.19	Resignation	2.07	Blaming Others	2.33
7	Social Withdrawal	2.16	Wishful Thinking	1.96	Wishful Thinking	2.15
8	Resignation	2.11	Blaming Others	1.89	Problem Solving	2.04
9	Wishful thinking	1.98	Social Withdrawal	1.81	Social Withdrawal	2.03
10	Self-criticism	1.82	Self-criticism	1.67	Self-criticism	2.01
	overall mean score	2.21	overall mean score	2.18	overall mean score	2.39

When the Spearman's rank correlation was applied to the data reported in Table 5.3, positive and significant relationships were found between helpfulness in different contexts: they are helpfulness in the illness related context and the blood test

(ϱ=.96, p<.001, N=10), the illness related context and the common context (ϱ=.99, p<.001, N=10) and the common context and the blood test (ϱ=.98, p<.001, N=10). These results indicate that the children found the coping strategies they did use helpful across contexts.

However, coping strategies that are often used were not automatically perceived as helpful by the children. For example, *Wishful Thinking*, 'I wish I could make things different' or 'I wish the problem (described earlier) had never happened' was widely used by this group of patients, the majority of whom used it in the common and the illness related context (ranked 1) and quite a few in the blood test situation (ranked 3). Although most of the children used Wishful Thinking, they did not find it particularly helpful (ranked 9, 7 and 7 respectively in terms of its helpfulness).

Cognitive Restructuring, 'I tried to see the good side of things', was most used during the blood test (ranked 1). Trying to see the good side of things seems a reasonable way to cope with a disliked, yet inevitable, medical procedure. But apparently it didn't help much (ranked 5). In the illness related context Cognitive Restructuring was ranked 5 and also reported to be only mildly helpful. In the common context, however, Cognitive Restructuring was ranked 8 for frequency and the children who used it found it very helpful (ranked 1).

In this study, where young patients with long term illness took part and talked about an illness related context and a blood test, *Self-criticism,* 'I blame myself for causing the problem', was rarely used and those who did use Self-criticism failed to find it a helpful way of coping with their stressors. This is in stark contrast, for example, to children in middle childhood going through a family breakup who are self-critical and tend to blame themselves (Wertlieb, 1991).

Table 5.4 A summary: intercorrelations between the coping strategies, their perceived helpfulness in three contexts (N=10)

	strategies			helpfulness		
	1	2	3	4	5	6
COMMON	-					
1 strategies	-					
ILLNESS	**ϱ=.72**	-				
2 strategies	***p*=.018**	-				
BLOOD TEST	ϱ=.24	**ϱ=.75**	-			
3 strategies	*p*=.498	***p*=.012**	-			
COMMON	ϱ=.23			-		
4 helpfulness	*p*=.521			-		
ILLNESS		ϱ=.37		**ϱ=.99**	-	
5 helpfulness		*p*=.290		***p*<.001**	-	
BLOOD TEST			ϱ=.45	**ϱ=.98**	**ϱ=.96**	-
6 helpfulness			*p*=.194	***p*<.001**	***p*<.001**	-

Examples of the children's coping and perceived helpfulness have been given above. The results reported in Table 5.4 confirm the findings. There is a weak association between two contexts and the children's use of coping strategies. However, a strong association was found between all three contexts and the children's perceived helpfulness. No significant relationship was established between the children's use of coping strategies and their perceived helpfulness.

Figure 5.2 is given as an example and illustrates the relationship between coping strategies used in the illness context and the perceived helpfulness for the same coping strategies in the same context (ϱ=.37, *p*=290, N=10).

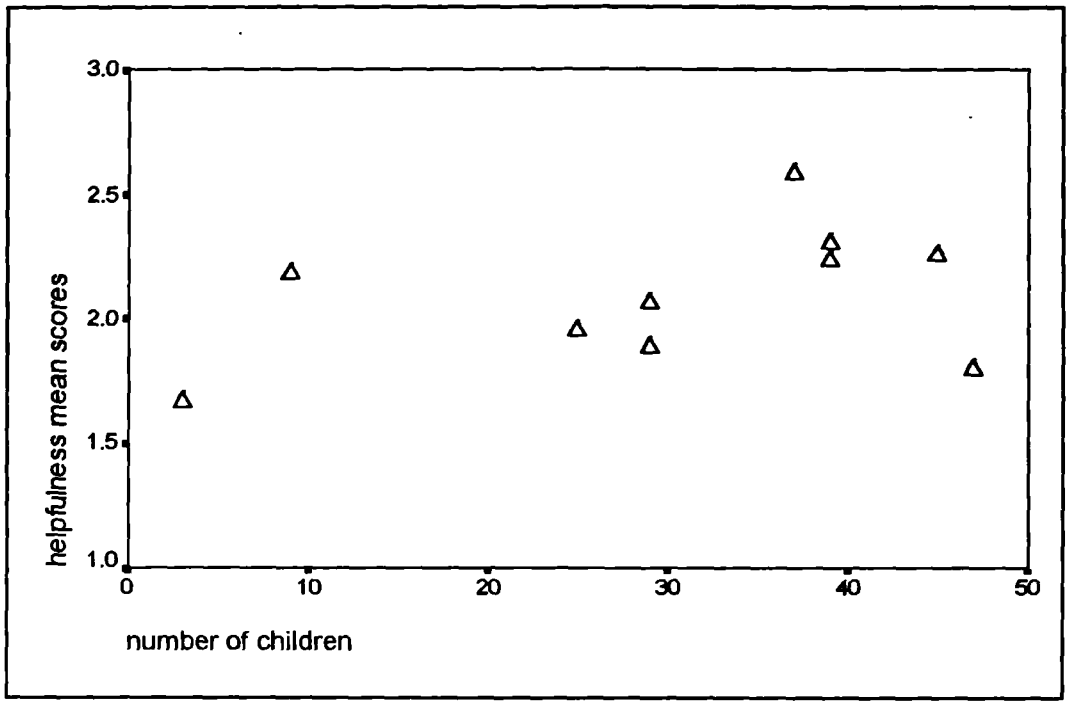


Figure 5.2 The illness context: the association between coping strategies used and their perceived helpfulness (N=10)

5.5.3 A summary of the data discussed so far illustrated graphically

Figure 5.3 is an illustrative summary of the results presented so far in the present study. It portrays the ten *coping strategies* and makes the link between the number of children who used a coping strategy and the perceived *helpfulness mean scores* within and across the *three contexts.* The relationship between these factors is complex and interesting. Similarities and differences are clearly visible, some of which should and will be explored further.

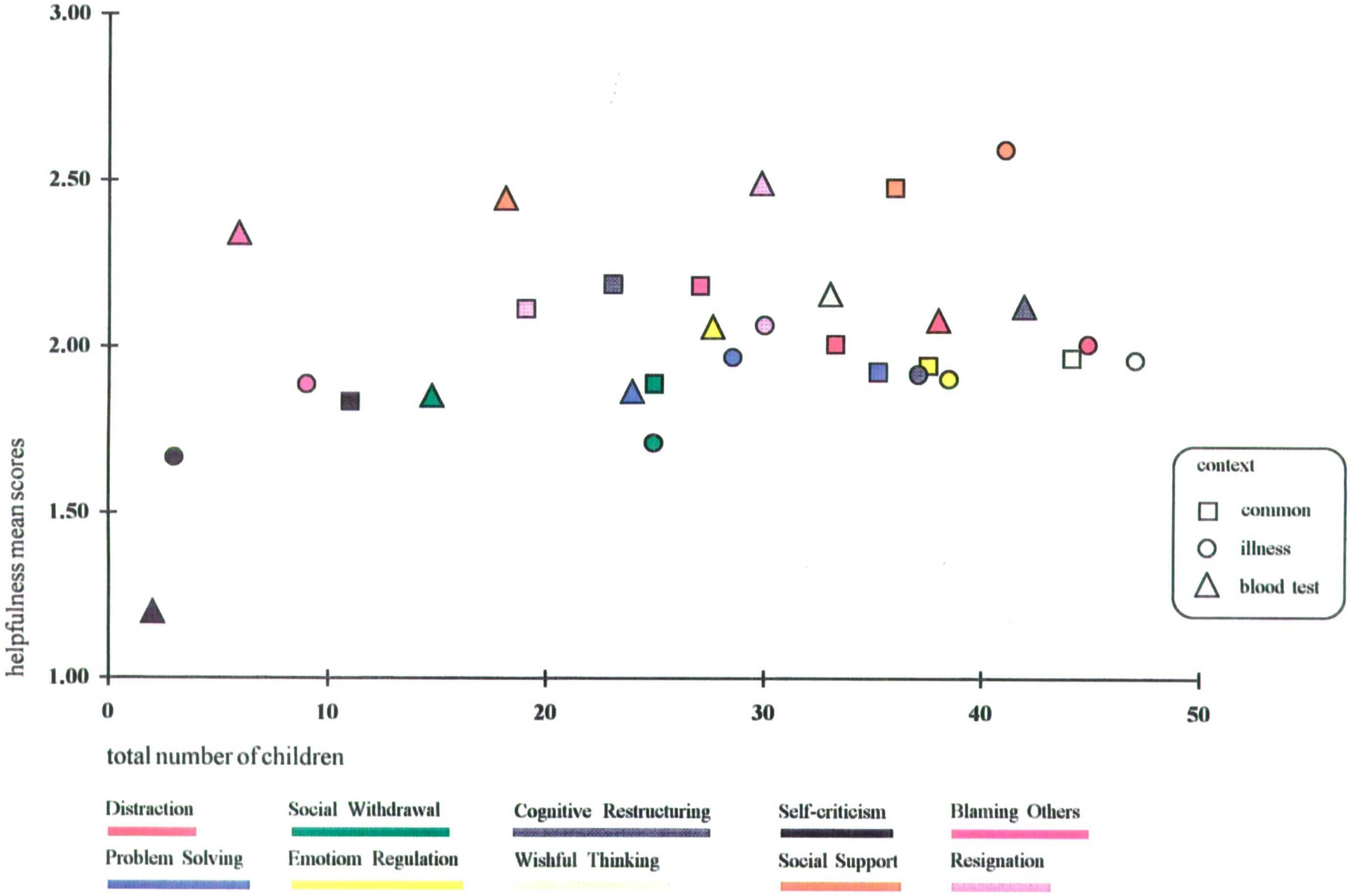


Figure 5.3 The relationship between coping strategies used and their helpfulness in three contexts

5.6 Differences of individual coping strategies across the three contexts: common, illness related and the blood test

Next, each coping strategy was looked at in turn across the contexts. Cochran 's Q, a test for dichotomous nominal data, was applied and the results are reported in Table 5.5. This distribution-free test is for more than two related samples, and provides a method for assessing whether these three matched sets of frequencies differ significantly among themselves.

Results show nine out of the ten coping strategies to differ between at least two contexts. This result is a strong indication that coping strategies are used to suit the stressful situation.

Table 5.5 The ten individual coping strategies across the three contexts (N=53)

coping strategy	**COMMON** frequency	**ILLNESS** frequency	**BLOOD TEST** frequency	Cochran Q	*p* value
Distraction	33	45	38	7.22	. 027*
Social Withdrawal	25	25	15	4.51	. 105
Cognitive Restructuring	23	37	42	19.51	. 001***
Self-criticism	11	3	2	14.01	. 001***
Blaming Others	27	9	6	24.93	. 001***
Problem Solving	36	29	24	9.94	. 007**
Emotion Regulation	38	39	28	7.66	. 022*
Wishful Thinking	44	47	33	11.24	. 004**
Social Support	36	39	20	20.06	. 001***
Resignation	19	29	30	11.57	. 003**

statistically significant differences between the groups at *** $p<.001$, ** $p<.01$ and * $p<.05$

The results reported in Table 5.5 show that 26 children said they had used the coping strategy of *Blaming Others* when describing an everyday problem, whereas only six children used this strategy when talking about the blood test. It appears that young patients are able to distinguish between situations and stressors, and whereas they tend to blame friends at school for teasing or hurting them, they don't blame the doctor for the fact that they have to give blood.

Another example taken from Table 5.5 is that in the illness related situation 39 children used *Social Support*, 'I tried to feel better by spending time with others like family or friends', as did 36 children in the common problem context. Only 20 used this strategy when coping with the blood test. These differences may stem from the patients being accustomed to the medical procedure and their awareness that the discomfort lasts only a short time and may 'do them good'.

With the exception of *Social Withdrawal*, the differences between the number of times a coping strategy was used within the context in which coping took place are shown to be significant (Table 5.5) and will be expanded on in Section 5.8.

Having looked at children's coping across the three contexts, and having found both similarities and differences, the scenarios, that is to say the specific *stressor types* in the common and in the illness related context, will be explored in more detail (Section 5.8). First of all, however, coping strategies used by an individual child across two contexts are compared and reported (Section 5.7). As the blood test context was a real-life stressor, specifically elected by the researcher and not by the children, it is left out of the analyses in Sections 5.7, 5.8 and 5.9.

According to the Folkman and Lazarus model, coping is related to any given situation. So far similarities and differences have been found within and across contexts, a finding which will be explored next.

5.7 Illness related stressors versus common stressors: comparing coping strategies used by the same child across the two contexts

When looking at coping and contexts, that is to say coping within (Section 5.8) and coping across a context (Section 5.6) and the individual coping patterns for each of the ten strategies across the three contexts (Section 5.5) both differences and similarities were found. For two reasons it is the common and illness related context that will be compared in this section. Firstly both of them include self-selected stressors and secondly so that a comparison can be made with previous studies (Chapter 3; Spirito *et al.*, 1995). Hence, it is the *individual child* and his or her choice of coping strategy across two contexts that is under investigation.

The kappa coefficient was calculated for each of the ten coping strategies in turn to assess an association between coping strategies used for the everyday stressor and the illness related stressor. Kappa takes into account the proportion agreement expected by chance in nominal data and its value falls between +1 and -1. In assessing the extent of agreement shown by the value of this coefficient it can be taken that the value of .75 or above shows excellent agreement and from .60 to .75 moderate agreement (Landis & Koch, 1977). Consistency *across the two contexts* (common and illness related) *described on the same day* by each child was not established. Kappa coefficients ranged from κ=-.44 for Social Withdrawal to κ=.38 for Resignation (N=53). It can therefore be concluded that in the present study consistency of coping between the two context was not found in individual children.

This result contrasts with the findings in Study 1, Section 3.8.3 where it was found that there was significant agreement between the coping strategies used by individual children *within the same context* (common or illness related) *but seven days apart.*

In the present study a child who uses a coping strategy when dealing with a stressor related to the everyday situation, does not necessarily use the same coping strategy when dealing with a stressor related to the illness situation. Coping was found to be

independent of the individual child but dependent on the context or situation in which coping takes place. This result may be partly due to the methodology of this study. Here the children were given widely differing contexts, an everyday-life situation and an illness related situation, to describe a stressor that had bothered them earlier. The resultant lack of consistency in coping may be twofold: firstly, the type of stressors, that is to say the context in which coping was reported to have taken place, are very different and secondly the sample was small. When the group of school children referred back to the same stressor in Study 1 they were found to have used similar coping strategies for both, the common context and the illness related context. However, the concept of the children's individual differences and their possible influence on the way they cope will be expanded on in Chapter 7.

5.8 Specific types of stressors reported within two given contexts

The children themselves nominated two of the three scenarios (common and illness related) while the third, the blood test, was provided for them by the researcher. They completed the Kidcope Checklist according to how they coped with each of the three stressors and throughout the interview related their answers to the specific stressor described earlier. Children have been seen to use varying numbers (Section 5.5) and various kinds (Sections 5.6 and 5.7) of coping strategies for different stressors in different contexts. This poses the question as to whether or not the *type* of stressor they chose *within* a given context might also differ, and if so, what *coping strategies* children use within that context (Section 5.9).

Traditionally researchers have looked for similarities and stability when assessing the coping process - with limited success. Explaining differences in the way children cope has been omitted from research literature. Here, the content analyses focused on a self selected, specific stressor within the predetermined framework of an *everyday* and an *illness related* problem. The content analyses in Sections 5.8.1 and 5.8.2 show children to be troubled by different types of stressor within different

contexts. These apparent differences are not surprising, yet must be seriously considered, when exploring stability or the lack of stability in the way children cope with stressful situations.

The *type* of stressor the children chose will be considered first. An informal content analysis of the stressors was carried out and illustrative examples appear below. Categorisation and inter-rater reliability are reported in Section 5.2. When looking at the content of the self-reported scenarios, it was found that children chose different types of stressors both within and between contexts. When discussing a *common* or everyday problem 57% of children described a *social* stressor (e.g. related to friends, bullying, conflict or separation), and when talking about an illness related problem, 55% of children described a *physical* stressor (e.g. related to the Hickman line, needles or their hair loss). The summarized results are presented in Tables 5.6 and 5.8 and examples given in Tables 5.7 and 5.9.

5.8.1 A common or everyday-life stressor: the scenarios and their content

As far as the common scenario was concerned, over half of the children reported a stressor that had occurred earlier at school while a quarter mentioned a stressor closely linked to life at home. Examples are given to illustrate these scenarios (Table 5.7). It was found that children chose different types of problems; 57% described a *relationship* problem (e.g. friends, bullying, conflict at home or separation) and 21% worried about *school work*. When describing a relationship problem 38% of the children reported *conflict* at school or at home as the stressor type.

Table 5.6 A common stressor type: content analysis of the 53 scenarios

School related			Home related		Medically related	Other	Total
Schoolwork	Friends	Bullying	Conflict	Separation			
11	7	10	10	3	8	4	53
21%	13%	19%	19%	6%	15%	7%	100%
	28		13		8	4	53
	53%		25%		15%	7%	100%

Table 5.6 summarises the stressors reported by the children, 30 (57%) are *socially* related stressors. Of the remainder 11 (21%) children referred to an aspect of school work as their stressor and 8 (15%) talked about the stressor related to the *medical* setting. Examples of the stressor types are given below in Table 5.7.

Table 5.7 Categorising stressors in the common context: descriptive examples

A school related stressor
School work:
"Home work is a real bore to me. Sometimes I get very upset because there is too much and I really feel I can't handle it. There is so much of it and an English Cup to compete for to top it all.. "
"I find Geography a problem at school, and my spelling is terrible. But by far the biggest problem is Geography. When I am in hospital I miss a lot of the work and it is difficult to catch up with the others. I had a Geography test and I was not prepared..."

Friends:

"I find it very hard to be in hospital without my friends. I like school and I have a lot of friends. I don't mind being here, I don't mind being in hospital but I miss my friends very much.."

"I have a school friend and he broke up with me. I still see him and we sometimes play together but he is not my friend any more. He now smokes and he is only 10 years old, imagine that. Anyway, it made me very sad ..."

Bullying:

"I have a problem at school with M. and E. E used to be my very good friend but now she is annoying and bossy. I feel left out and I would like to have a best friend. The worst of it is that they tease me and sometimes hit me. They gang up on me. I have talked to my teacher and to my mum. They waited outside the school gate.."

"At school a group of girls are bullying others, and especially me. They tease me, they say that I am teacher's pet and that I am brainy and that is horrible. The other day they had a go at me and some of my friends..."

A home related stressor

Conflict:

"I had a problem with my mum. I had a messy room and mum got very cross. I like to go out and play and forget about it. I hate tidying my room and I get cross when she gets cross.."

"My problem is my brother. We fight a lot. The other day we had a fight and it got out of hand. I got stuck behind the Telly and I got worried. He is very strong.."

Separation:

"I miss my brother and sister very much when I am in hospital. Yesterday I had a very bad day. I was very homesick and I was thinking of them a lot. It was my idea to ask if they could visit here. They are coming on Friday..."

"I miss my brother very much we are nearly the same age and we play a lot (this boy is the youngest of seven children). The biggest problem is that I am home sick.."

A medically related stressor

"The Hickman line is a nuisance. I don't like it. When the class goes swimming I can't go. Last week I got very upset. I can't even have water fights because the line can't get wet..."

"I don't like being hooked up to a drip. I can't go very far with this thing. Last night I got all tangled up and there was no one to help me..."

Others
"My dog died two weeks ago. What happened was that he got killed by a car. A man knocked on the door and told my mum that he was dead, he had been run over by his car. I am very upset because I never saw him dead..."
"When my favourite doll broke I cried a lot. She was very old but I used to sleep with her every night. No, I don't think she can ever be replaced..."

These examples of everyday stressors are presented to illustrate the categories which were established (Section 5.2) and reported in Table 5.6.

5.8.2 An illness related stressor: the scenarios and their content

The results in Table 5.6 of the content analysis for the everyday stressors can be compared, by inspection, with the results of the illness related stressors, which are analysed and summarised in Table 5.8. Distinctions between the two contexts and the types of stressor the children talked about within the contexts are clearly visible.

Table 5.8 An illness related stressor type: content analysis of the 53 scenarios

School	Home	Medically related						
related	related	Procedures			Consequences		Other	Total
Friends	Separation	Hickman	Needle	Other	Physic.	Mental		
6	1	8	8	8	13	7	2	53
11%	2%	15%	15%	15%	25%	13%	4%	100%
6	1			44			2	53
11%	2%			83%			4%	100%

Table 5.8 summarises the stressors reported by the children, the majority of which are *medically* related. Forty four (83%) children talked about a stressor connected to their disease such as losing their hair, feeling depressed, and worries they have with injections or the Hickman line. Only seven children described a *socially* related stressor at home or at school. Examples of scenarios are given in Table 5.9 to illustrating the stressor types.

Table 5.9 Categorising stressors in the illness related context: descriptive examples

A school related problem
Friends: "I really miss my friend from school while I am here on the ward. I have to spend a lot of time in the hospital either here or in out-patients and so I can't see my friends. A few days ago I felt really 'friendsick'.." "Because I have to go in and out of hospital I find I lose touch with some of my friends. I miss a lot of time at school. They go out and I miss the parties and sport like football. The other day.."
A home related stressor
"I am very home sick. The family can't visit, only my mum, and I can't go home yet, I will I hope..."
A medically related stressor
Medical procedure/Hickman line: "The thing that annoys me most about having Leukaemia is having a Hickman line. I can never go swimming with the rest of the class. Last week the same thing happened again. I am left out of the fun..." "The 'wiggly' is sticking out and I don't like it. It is there all the time and never goes away. It is uncomfortable. The other day I nearly pulled it out by mistake.."

Medical procedure/Needles:

"I get very worried when they use long fat needles in my left hand. No, I don't have a Hickman line and all my injections have to go in my left arm and I don't like it.."

"Gosh, I don't like needles at all. I don't mind finger pricks but needles I definitely do not like. Last week they had to take blood with a needle. You were there and saw how I hated it. I cry like a baby.."

Medical procedure/Others:

"You know those robots which are used for the medicine and the blood, I mean it is put through the Hickman line. This thing stops me from moving, especially going to the play room. There I can't go up the stairs with it. I tripped and nearly caused and accident..."

"I had an x-ray while stuck in bed. They pushed me out of the ward and into the lift and on my bed to the x-ray department. It was very embarrassing..."

Consequences of the illness and/or treatment/Physical:

"I really don't like to be sick or feeling sick. The chemotherapy can make you feel terrible. When I had my bone marrow transplant and before I was sick a lot. It's not like eating too many cakes because you can fight that. You can stop eating so much and you feel better the next day. When your sickness is because of the medicine it is really hard. Yesterday I was sick again.."

"All my hair is falling out. I think about it all the time. It's on my pillow and all over the floor. I worry a lot about what I am going to look like and I don't know if I should have a wig or maybe a cap.."

Consequences of the illness and/or treatment /Mental:

"I feel very fed up and depressed about being here and about my illness. You know I was better and now it has come back again. This time I know what it is like..."

"Being on the ward makes you very lonely and sad. I get sad every day, especially at night time when I should go to sleep.."

Others

"The ward is very noisy at night. The little kids scream and I am not allowed to read or turn the TV on. I hate the night time here..."

These examples of illness related stressors are presented to illustrate the categories which were established (Section 5.2) and reported in Table 5.8.

The result of the content analysis and the variation in the types of stressor reported by the children in two contexts will be expanded on in Section 5.9. Although expected these differences must be taken seriously and should form the basis of any future investigation into children's way of coping. From looking at the established differences it is possible to further explore the coping process related to stressor types and to find similarities and/or differences between the kind of coping strategies the children used.

5.9 Common and illness related scenarios: types of stressor and the way children cope with them within a context

Having touched on the importance of the context affecting the way these children cope, and having looked at the content of the common and illness related scenarios, the *types of stressor* within a context will now be explored as well as the *coping strategies* used.

As was discussed, the two self-selected stressors within the common and the illness related context under investigation in this study elicited different responses from the children. The sample is small and the issues are complex. However, from the results reported so far it can be assumed that it is not only the context that should be carefully considered but the type of stressor within a context.

A variation of stressor types produces a variation in the number and the kind of coping strategies used. When looking at and considering consistency and predictability of coping in children, it will be important to begin any future investigation by looking at similar stressors in similar situations. For example, asking a child to recall a stressor related to life on the ward and a stressor related to a

medical procedure and comparing the two might show related coping patterns. Looking at stressors in similar contexts and gradually extending the variability may be a constructive alternative to looking at individual differences and stability and predictability within the individual child. This is an area of research, which goes beyond the scope of this study.

Nevertheless, the above mentioned ideas were explored a little further. Given the existing data set, it was the stressor types in the *home* setting versus the stressor types in the *school* setting in the everyday context as reported in Section 5.8.1 and the stressor types in the *procedures* category versus the stressor types in the *consequences* category in the illness related context as reported in Section 5.8.2 that were looked at in detail. By definition this method will not include all the children who took part in the study, nor is the sample related between the two contexts.

5.9.1 A common or everyday-life scenario: stressor types and coping

The *school* related stressor has three categories: school work, friends and bullying whereas the *home* related stressor is made up of just two categories: conflict and separation. Twenty eight of the 53 children related to the stressor in the everyday-life context to the school situation and 13 of the 53 children to the home situation. The everyday-life context allows for diverse stressor types.

Table 5.10 Stressors in the common context: comparing stressor types in the school and in the home setting (n=41)

rank	SCHOOL (n=28)		HOME (n=13)	
	coping strategy	%	coping strategy	%
1	Wishful Thinking	79	Wishful Thinking	85
2	Problem Solving	75	Problem Solving	69
3	Distraction	71	Blaming Others	69
4	Social Support	71	Emotion Regulation	69
5	Emotion Regulation	68	Cognitive Restructuring	62
6	Social Withdrawal	57	Distraction	46
7	Blaming Others	46	Social Support	39
8	Cognitive Restructuring	39	Social Withdrawal	39
9	Resignation	36	Resignation	31
10	Self-criticism	25	Self-criticism	23

Spearman's rank correlation was used to look for an association between the two stressor types. A weak association between stressors in the home and stressors in the school setting in the everyday context was found (ϱ=.66, p=.036, N=10). As illustrated by Table 5.10, children used similar coping strategies within the common context, the two top and the two bottom rankings being of equal standing.

5.9.2 An illness related scenario: stressor types and coping

The medically related stressor within the context of the child's illness included both *procedure* (Hickman line, needle and other) and *consequences* (physical and mental). Twenty four of the 53 children related their stressor to a medical procedure and 20 of the 53 children to the consequences following their illness.

Table 5.11 Stressors in the illness related context: comparing stressor types in the medical setting (n=44)

rank	PROCEDURE (n=24)		CONSEQUENCES (n=20)	
	coping strategy	%	coping strategy	%
1	Distraction	88	Distraction	85
2	Wishful thinking	88	Wishful thinking	85
3	Cognitive Restructuring	75	Social Support	85
4	Social Support	71	Cognitive Restructuring	75
5	Emotion Regulation	71	Emotion Regulation	75
6	Resignation	67	Problem Solving	71
7	Social Withdrawal	46	Resignation	55
8	Problem Solving	42	Social Withdrawal	51
9	Blaming Others	13	Blaming Others	15
10	Self-criticism	4	Self-criticism	11

Again, Spearman's rank correlation was applied and similarities between the two stressor types were found (ϱ=.91, p<.001, N=10). As reported in Table 5.11, children used comparable coping strategies within the illness context; between stressors related to a medical procedure and stressors related to the consequences of the illness. Five out of ten coping strategies were ranked equally between the stressor types, showing some consistency in the way children coped with their stressor.

This result is interesting and confirms the notion, first raised in Section 5.5, of the importance of the situation or context in which coping takes place. Based on the results to date, a coping pattern was identified. The more similar the contexts, in which the stressors occur, the more likely it is that children will use similar coping strategies. In other words, to find out more about coping patterns, researchers

should start by asking children to relate similar situations and widen the issue only once a more stable pattern is established.

5.10 Self-reported distress: a part of the Kidcope Checklist

Having looked at the way children cope in different contexts the *distress* part of the Kidcope Checklist was analysed. Children reported how they felt about stressors in the three contexts: a common and an illness related context and the blood test.

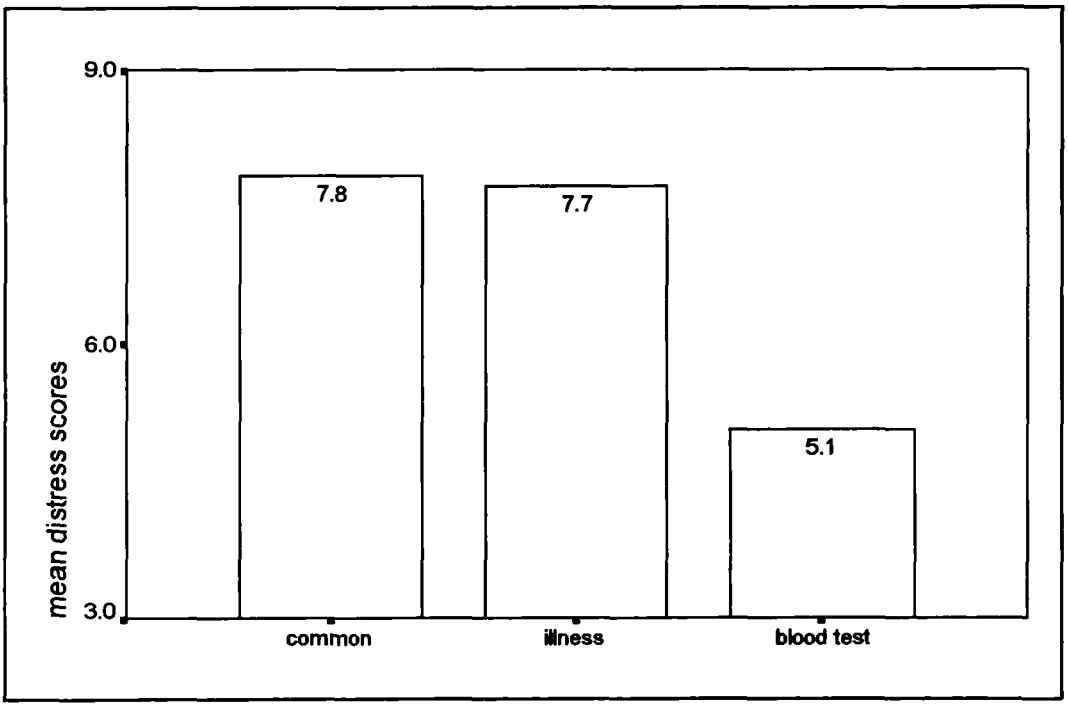


Figure 5.4 The three contexts: comparing the self-reported distress scores

In this study *distress*, the emotional response to a stressor, is made up of three factors: "Did that time make you feel.... *nervous* or *anxious; sad* or *unhappy; cross* or *angry*?" each of the three questions was answered on a 5 point Likert-type scale

and the distress score was made up by adding the three *factor* scores each ranging from 1-5. The possible range for the *distress* score is 3-15 for each of the three contexts. Inspection of Figure 5.4 shows the children were feeling more distressed when reporting a stressor, which was chosen by them than the one selected for them. Overall, the blood test stressor was reported to be the least distressing of the three stressors. This finding is comparable to the number of coping strategies children used for the same stressors (illustrated by Figure 5.1) and is looked at in more detail (Figure 5.5 and Table 5.12).

Table 5.12 Self-reported distress as measured by Kidcope across the three contexts (N=53)

	COMMON		ILLNESS		BLOOD TEST	
distress factors	mean	*SD*	mean	*SD*	mean	*SD*
nervous/anxious	2.57	1.34	2.49	1.49	2.11	1.38
sad/unhappy	2.53	1.31	2.91	1.38	1.49	0.89
cross/angry	2.75	1.49	2.31	1.41	1.45	0.91
distress	7.83	2.90	7.72	3.13	5.06	2.73

The mean scores show that the children tended to feel cross but less unhappy and nervous in the common context. When rating the illness related stressor they felt unhappy yet less anxious or cross, whereas when rating the blood test they felt anxious yet less unhappy or cross. When the three factor scores were combined to make up the distress scores, significant differences between the contexts were found. As with the coping strategies, these results confirm cross situational variability, in which the children reported feeling distressed to varying degrees, according to the context.

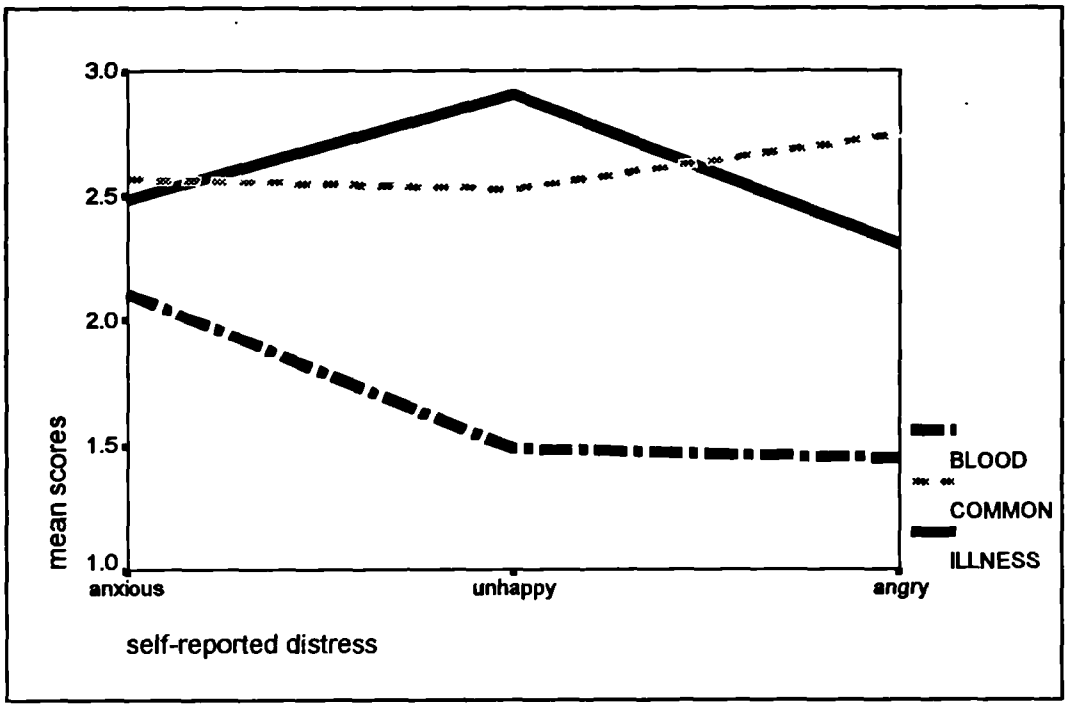


Figure 5.5 Self-reported distress across the three contexts

A multivariate analysis of variance was employed to compare the three distress mean scores within 53 subjects. The variable *context* has three factors (common, illness related and blood test) and so does the variable *distress* (nervous, sad, cross). The between-subject effect $F(1,52)=665.25$, $p<.001$ was significant. The Mauchley sphericity test was non-significant and therefore it was not necessary for the degree of freedom estimates for the averaged results to be adjusted. A significant context effect was found $F(2,104)=18.26$, $p<.001$. When inspecting Figure 5.5 it can be seen that the effect stems mainly from differences between the self-selected stressors (in the common and illness related context) on one hand and the specific stressor (the blood test) on the other.

When assessing differences between the three distress factors it was found that the Mauchley sphericity test involving distress within-subject effect was significant ($p=.030$) and the degree of freedom estimates had to be adjusted by using the

Greenhouse-Geisser Epsilon. However no significant difference was found between the three distress factors F(1.77, 92.14)=1.43, p=.245. Next, the Mauchley sphericity test involving context by distress within-subject effect was non-significant. Therefore the degree of freedom estimates were not adjusted. The results involving context by distress are F(4, 208)=5.53, p<.001, and confirm interaction. The interaction between the three distress factors and the contexts is illustrated by Figure 5.5.

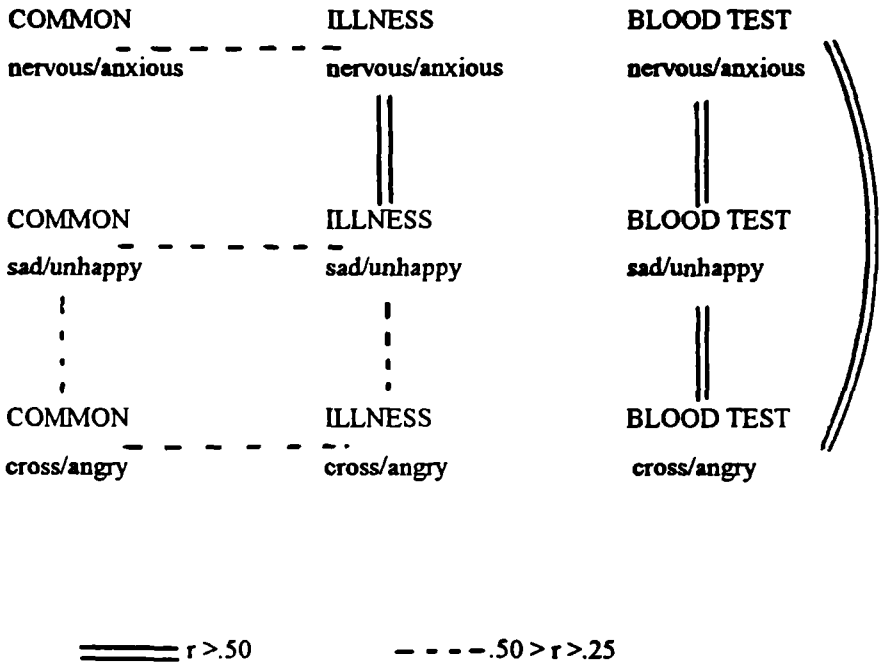


Figure 5.6 Correlation patterns between context and distress

The three distress factors within the blood test context are associated with each other, but are independent from the common and the illness related context. Children, who reported feeling sad or unhappy during the blood test and children, who reported feeling sad when recalling a stressor in the illness related context, also felt nervous or anxious. Within each of the three contexts feeling sad or unhappy was also associated with feeling cross or angry (Figure 5.6).

5.11 Distress and coping strategies: their relationship

As reported in Section 6.6 the distress part of the Kidcope Checklist was validated by correlating the children's self-reported distress and their distress behaviour during a blood test. It is therefore valuable to look at the association between the intensity of the self-reported distress and the number of coping strategies used by the children to deal with their stressors. It is possible that children who use more coping strategies also feel more distressed.

Table 5.13 Correlation coefficients between distress and coping (N=53)

	COMMON **strategies**	ILLNESS **strategies**	BLOOD TEST **strategies**
COMMON **distress**	r=.39 p=.004		
ILLNESS **distress**		r=.53 p<.001	
BLOOD TEST **distress**			r=.52 p<.001

Pearson's product-moment test was used after inspecting the scatterplots and distributions of the above reported variables. The coefficients and probabilities are reported in Table 5.13. A significant association between the number of coping strategies the children reported to have used (with a possible range from 0-10) and the intensity of their self-reported distress (with a possible range from 3-15) *within* each context was found. The consistency of these results reinforces the results of the Kidcope Checklist.

5.12 A summary of the results

A self-report instrument was used to explore the way the children with a serious illness coped in three situations. They talked about the nominated stressor and two specific, personal stressors. The results show coping to be highly influenced by the situation in which the stressor occurred and was dealt with. The children used more coping strategies when dealing with an everyday-life and an illness related situation but thought them less helpful than the fewer coping strategies used to deal with the blood test, i.e. applying a coping strategy did not automatically help. These findings are illustrated by Figure 5.3.

Although consistency in the way the individual child coped was not established *across* the everyday-life and the illness related context, it was found that patterns *within* a context, for example stressors within the illness related context, do exist. Both these areas require further exploration. In future studies with larger groups of children the Kidcope Checklist should be completed and the personal stressor should be chosen from three similar contexts and coping compared (for example, medical situations in the hospital such as a BMA, getting an injection and taking foul tasting medicine orally), so that a coping pattern within the coping process framework can be established as a basis for further research.

As with the coping strategies, the way the children felt about their stressor was related to the situation. That is to say that the children felt more distress when dealing with an illness related stressor than with the blood test. This result was confirmed through strong associations between the total number of coping strategies they used and the amount of distress they felt.

If coping is a process (Lazarus & Folkman, 1984) then the assessment instrument should allow for variability and change. Kidcope does just that. In Study 1 it was found to be a reliable instrument when the same children reported on the same stressors eight days apart. However, in the present study when the same children

reported on different stressors during one interview - situational variations were established.

Having considered the children's coping process through one-to-one interviews, these findings will be extended in Study 3 by results from direct observations. Each child was observed during one of his or her routine blood tests, and the procedure and results are reported in Chapter 6.

CHAPTER SIX

OBSERVED DISTRESS AND COPING BEHAVIOUR

Study 3

The distress behaviour and the coping behaviour observed during a blood test form the basis of Study 3 and combined with the results reported in Chapter 5 make up *the core of coping*. First the two instruments, the Observation Scale of Behaviour Distress (OSBD) and *taking an active or taking no interest in the medical procedure*, will be discussed, then the two procedures will be related and the results presented in the second part of this chapter.

Research questions:

> How do the distress behaviour scores (OSBD) compare with the distress scores reported in the Kidcope Checklist in respect to the blood test?
>
> What is the relationship between children's observed distress (OSBD) during a medical procedure and their coping behaviour?
>
> What is the relationship between children's self-reported distress (Kidcope) during a medical procedure and their coping behaviour?

The same researcher observed all 53 children on separate occasions during a routine blood test in a London teaching hospital. Observation and self-reported results include data from the OSBD, the coping behaviour and the distress part of the Kidcope Checklist.

METHOD

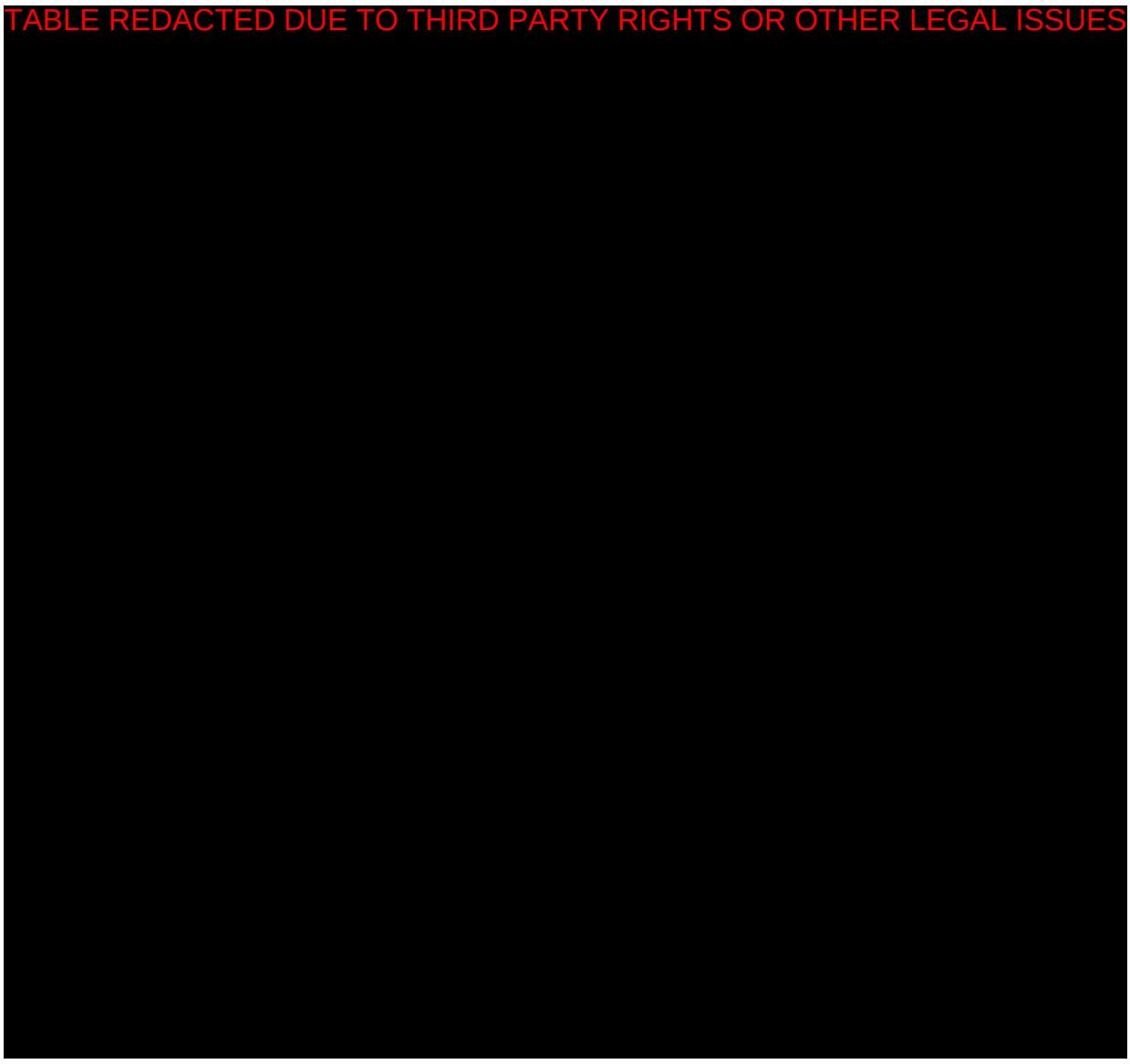
6.1 The Observation Scale of Behaviour Distress - OSBD

Structured observations aim to be objective. They measure behaviour accurately and reliably, and restrict partiality. Data are collected in a planned and systematic way. The role of the observer is essentially that of a 'follower of instructions', with the instructions laid down in the observation schedule. The structured method is based on rigorously defined categories of behaviour, defined and outlined before the start of the data collection (Pretzlik, 1994). When observing distress behaviour experienced by children, particularly those in a medical setting, a systematic approach is called for. To devise possible interventions appropriate to the reduction of stress it is necessary to have a precise measure for looking closely at factors associated with children's distress and coping with stressful treatments (Sylva, 1992).

A reliable and valid instrument to record and measure *behavioural distress* during a medical procedure involving children was developed by Jay and her colleagues (Jay *et al.*, 1983; Jay & Elliott, 1984) and revised by Jay and Elliott (1986). It was the revised version, the OSBD, that was used in this study. The original OSBD consisted of 11 behavioural categories: Information Seeking, Cry, Scream, Physical Restraint, Verbal Resistance, Seeks Emotional Support, Verbal Pain, Flail, Verbal Fear, Muscular Rigidity and Nervous Behaviour. When subjected to an item analysis it was found that eight of the eleven categories fitted the set criterion. Three behaviour categories were left out of Jay and Elliott's (1986) version (Fear, Muscular Rigidity and Nervous Behaviour).

Table 6.1 lists and defines the eight behaviour categories which make up this observation scale.

Table 6.1 The behaviour categories for the OSBD (Jay & Elliott, 1986)



6.1.1 Validity of the OSBD

OSBD scores of individual children were compared with other measures of distress and anxiety to test the validity of the scale. Jay *et al.* (1983) observed 42 paediatric cancer patients between the ages of two and 20 undergoing a bone marrow aspiration.

The OSBD was used to measure distress behaviour during continuous 15 second intervals. The scores were weighted according to the intensity of distress behaviour (Section 6.4.1.1) and compared with the parents' ratings of their children's anxiety at the time of the hospital visit (r=.38, p<.05, N=42). Correlations between observed behaviour and parental ratings were modest and explained some of the variance (14%) but leaving 86% unexplained. A comparison was made between children's self-ratings of anticipated pain levels prior to the bone marrow aspiration and distress behaviour (r=.75, p<.001, N=42). It explained 56% of the variance.

Elliott, Jay and Woody (1987) also validated the OSBD with young cancer patients. They observed 55 children during a bone marrow aspiration. The patients' age ranged from 3 to 13 years. Once again the OSBD was used during continuous 15 second intervals. Employing the same method as Jay *et al.*(1983) the behaviour scores were weighted according to the intensity of the distress (Section 6.4.1.1). Distress-related behaviours were correlated with self-report measures of fear (r=.38, p<.01, N=55), and physiological measures of diastolic (r=.38, p<.01) and systolic blood pressure (r=.32, p<.01). These associations although statistically significant are weak, leaving a large proportion of the variance (86%) unexplained. The patient's heart rate (r=.55, p<.001) and the nurses ratings of children's distress (r=.69, p<.001) were also compared with the distress behaviour. Here stronger associations between the distress behaviour and the children's heart beats and the nurses' reports were found.

The results of both these studies showed some association between the OSBD behaviour scores and other measures of distress, such as self-reported fear and physiological arousal. Although there is much support for the validity of this instrument reported in the literature (Jay & Elliott, 1986; Elliott *et al.*, 1987) this evidence should be viewed with caution.

6.1.2 Reliability of the OSBD

The inter-observer reliability of the OSBD has been documented in several studies (Jay *et al.*, 1983; Jay & Elliott, 1984; 1986) and has proved to be excellent. Reliability in the studies reported here was calculated by dividing the number of agreements within each 15 second interval by the total number of agreements plus disagreements. Independent reliability checks were conducted during medical procedures. The results of percent agreements are good and are reported to range from 80% to 84%.

Elliott *et al.* (1987) assessed inter-observer reliability. Total OSBD scores for two observers were correlated using Pearson's product-moment correlations analyses (r=.98, p<.001, N=55). With a high correlation coefficient 96% of the variance was explained and strong support for the reliability of the OSBD was established. Possibly this may be due to the low-inference behaviour categories and their clear definitions. The behaviour categories are relevant to many medical procedures and are quick and easy to record on the OSBD checklist.

6.2 Taking an active interest in the blood test

For the purpose of this research, and as an independent measure, the *taking an interest in the blood test* coping behaviour category was added to the OSBD behaviour checklist. Here, a child is defined as a coper with an *active interest* if he or she looks at the needle going into the skin and watches the blood coming out. A child who shows none of the 'taking an interest in the blood test' behaviour, i.e. takes no active part in the blood test or simply ignores it or looks away deliberately, is defined a coper who *lacks interest.* This coping behaviour was coded for its presence or absence during four 15 second intervals in the treatment phase.

The two coping behaviour categories were first used while observing 12 children in the pilot work (Section 4.3.2). Inter-observer reliability was tested and found to be high. The results are reported in Section 6.3.

6.3 Inter-observer reliability in this study

One aspect that effects reliability is that of the judgement between raters. In this study inter-observer reliability for the *eight OSBD categories* and the added category of *active interest* coping behaviour was established. Eighteen children between two and 12 years of age were observed during a routine blood test in a London teaching hospital. All the children were cancer patients but none were included in the final research sample.

The reliability exercise was carried out by two raters - rater A (the researcher) and rater B (another qualified psychologist). The observers sat discreetly near the phlebotomist and the observed distress behaviour was entered on the OSBD checklist by ticking the appropriate boxes during the anticipation, treatment and recovery phase (the phases are defined in Section 6.4.1.1). Interested coping behaviour was observed and recorded for its presence or absence during the treatment phase. A bleeper with a joint earpiece defined the continuous 15 second intervals.

Table 6.2 Inter-observer reliability coefficients for the OSBD and the 'taking an interest' coping behaviour

The eight OSBD categories and taking an Active Interest								
Inform Seeking	Cry	Scream	Restraint	Verbal Resist	Emotion Support	Verbal Pain	Flail	Active Interest
1. 00	1. 00	.82	1. 00	.85	.88	.85	.64	.84

Inter-observer reliability was tested using kappa for polychotomous data, subject by subject. Results for the eight distress behaviour categories and the coping behaviour category are reported in Table 6.2.

Kappa is a reliable coefficient taking into account the proportion agreement expected by chance in nominal data (Zwick, 1988). The value of kappa falls between +1 and -1. In assessing the extent of agreement shown by the value of kappa it can be taken that a value of .75 or above shows excellent agreement beyond chance and from .60 to .75 only moderate agreement (Landis & Koch, 1977). It can therefore be said that with the exception of the one category *Flail*, the inter-rater reliability shows excellent agreement. *Flail* was left out of the final analysis. The children in the main study did not use the one behaviour category Flail. This will be discussed in Section 6.5.

When tested the *taking an active interest* coping behaviour category showed high reliability (Section 6.4.2). The kappa coefficient was .84.

6.4 Distress behaviour and coping behaviour: the procedure

The application and scoring of the OSBD and the coping behaviour (taking an active interest during a medical procedure) as devised in this study will now be discussed in more detail. All data were collected on separate occasions, one by one, within the hospital setting by the same researcher.

6.4.1 Observing a medical procedure - the blood test

Most research about distress in patients involves observing or talking about a painful medical procedure. In this study the patients were observed during one of their routine blood tests. As discussed in Chapter 5 the same children were asked to complete the Kidcope Checklist after the blood test had been observed. During the one-to-one interview they talked about the distress they felt while having had their

blood taken. The self-reported distress element of Kidcope is made up of three distress factors: feeling nervous or anxious, sad or unhappy, cross or angry.

Blood tests form an important part of the lives of children with leukaemia and aplastic anaemia. They experience countless blood tests during their illness and even during periods of remission. Often, during the acute period of their treatment, a Hickman line is used. A Hickman line is a fine plastic cannula inserted into a vein in the neck or chest. This plastic tube allows the regular administration of drugs and the repeated taking of blood samples without pain and with minimal discomfort to the patient. Although patients with Hickman lines occasionally have conventional blood tests, these do not take place on a regular basis. Whenever a blood test was scheduled for one of the patients in this study, the researcher made an appointment to observe it. Sometimes that involved a delay of days or even weeks.

By the time the observation did take place, the patient was familiar with the researcher and took little notice of her. The researcher placed herself unobtrusively and carried out the observations discreetly. The blood test took place either on the ward or in a specially allocated room and was always administered by an experienced doctor, nurse or phlebotomist. The members of the medical team were also familiar with the researcher and her presence.

The OSBD consists of eight distress behaviours (Table 6.1 and Appendix V) which are coded for their presence or absence during each interval. Four intervals make up one phase and three phases make up a complete observation. Multiple behaviours were registered on a recording sheet during these regularly timed intervals. Intervals were defined by the sharp sound of an automatic bleeper. The researcher carried the bleeper in her pocket and the earpiece was pulled through the lapel of her jacket. The wire was hidden by the combination of clothing and long hair. In the present study the children's distress behaviour was recorded in continuous 15 second intervals and corresponds with other relevant and related research (e.g. Jay & Elliott, 1984; Elliott *et al.*, 1987; Wiltshire, 1992).

Blood tests, like other medical procedures, can vary considerably in the total time they take. The time variation may be due to patients' behaviour, the medical staff or the availability and functioning of the equipment. To overcome this difficulty and to avoid the OSBD scores getting distorted, Jay and Elliott (1986) suggest that a pre-specified number of intervals for each phase should be scored and reported. In this study, however, the length of the three phases was determined after measuring the length of each phase during the medical procedure. The phase lengths were taken as the median scores from the total number of intervals observed during the *anticipation, treatment* and *recovery* phase.

6.4.1.1 Defining the three phases

1. Anticipation phase

> *Before treatment:* Recording started as the doctor, nurse or phlebotomist made contact with the child and ended once the skin area was disinfected and ready for the needle to go in. The anticipation phase consisted of no more than four intervals. The intervals were counted back from the beginning of the treatment phase. If the treatment phase began before four intervals had passed, then, whatever intervals occurred were scored.

2. Treatment phase

> *During treatment:* This period of recording began once the needle touched the skin and ended once the needle was pulled out and the sensitive area had been covered with a cotton bud. The first four or less intervals were scored.

3. Recovery phase

> *After treatment:* Four intervals made up the recovery phase. The intervals followed directly on from the treatment phase or from the moment the cotton bud was applied. If this phase consisted of less than four intervals then whatever number of intervals occurred were scored. The doctor, nurse or phlebotomist labelled the blood sample before getting a plaster ready. The recovery phase was terminated once the plaster was in place.

6.4.1.2 Scoring the OSBD according to Jay and Elliott (1986)

1. Frequencies of each behaviour category are added for the intervals within each of the three phases.

2. The number of intervals scored for each phase are recorded.

3. Each behavioural category frequency score is then divided by the number of intervals scored in each phase. This score becomes the *mean interval score.*

4. Each of the mean interval scores is then multiplied by its assigned intensity score. This produces a *weighted mean interval score.* Each behaviour category is weighted according to its intensity so that behaviours such as *scream* are given more importance than behaviours such as *Information Seeking.* The scores are multiplied by frequency scores and the intensity scores are as follows (Jay & Elliott, 1986):

   Information Seeking (1.5); Cry (1.5); Scream (4.0); Physical Restraint (4.0); Verbal Resistance (2.5); Emotional Support (2.0); Verbal Pain (2.5) and finally Flail (4.0).

5. The weighted mean interval scores are added across categories, to give a subtotal for each of the three phases.

6. The three weighted phase scores are added and the *total distress score* is recorded.

7. The number of intervals, 15 seconds each, is added across the three phases. They give a score for the *total time taken.*

The *parental presence* or *parental absence* during the blood test and the place from which the blood was taken (*finger, hand* or *arm*) were recorded with a simple *yes* or *no* answer. The place of insertion does not form part of a research question and is not included in the later data analyses. Results related to parental presence or absence forms part of the analysis in Study 5.

6.4.2 The taking an active interest coping behaviour

The child's 'taking an active interest during the blood test' coping behaviour was also observed and coded for its presence or absence. Disinterested copers took no part in the blood test while interested copers looked at the needle going into the skin and the blood coming out. This coping behaviour was observed at the same time as the distress behaviour and was recorded on the OSBD checklist. Observations of this coping behaviour took place during four continuous 15 second intervals in the treatment phase of the medical procedure and were recorded as an additional category on the checklist. Reliability data of the added behaviour category are reported in Section 6.3.

RESULTS

Observational data forms the basis of Study 3, and together with results reported in Chapter 5 make up the core of coping as defined in this thesis. Children's distress behaviour during a routine blood test is reported and assessed in Sections 6.5.1 and 6.5.2. Validation of the Kidcope distress element has been possible by combining observational and self-report methods (Section 6.6). Finally, observed distress behaviours between patients and their coping behaviour and self-reported distress are compared and results reported in Section 6.7.

6.5 A blood test: observing the children's distress behaviour

The distress behaviour has a possible range of 0 to 84; it was assessed across 7 categories during 12 regular intervals. Initial inspection of the data revealed that children's OSBD scores are skewed with a range of 0 to 23. Ten children (19%) have zero scores. A natural logarithm transformation was applied after adding 0.5 to all scores and, as a result of this, the distribution shows less deviation from the normal

curve. Therefore parametric analysis was used, where appropriate, for the OSBD scores. Transforming the OSBD observational data and analysing it using parametric methods is in accordance with other research (e.g. Elliott *et al.*, 1987; Wiltshire, 1992). Bradford (1990), in his study, eliminated the zero scores to create a more Normal distribution. This method was rejected as much valuable data would have been lost.

The total behaviour distress scores for each of the *three phases* are illustrated by Figure 6.1 and the total behaviour distress scores for each of the *seven behaviour categories* are illustrated Figure 6.2. One behaviour category on the OSBD, Flail, is omitted all together from the analyses. Possibly due to the age of the children, Flail, 'random gross movements of arms legs or whole body', was not seen during these observations. When necessary, children in this age group were willingly restrained. Flail is more likely to be seen in infants and toddlers than in children and young people aged 7 to 16 years.

6.5.1 Distress behaviour during three phases

The OSBD mean weighted interval scores for the three phases, before the natural log transformation, are illustrated by Figure 6.1.

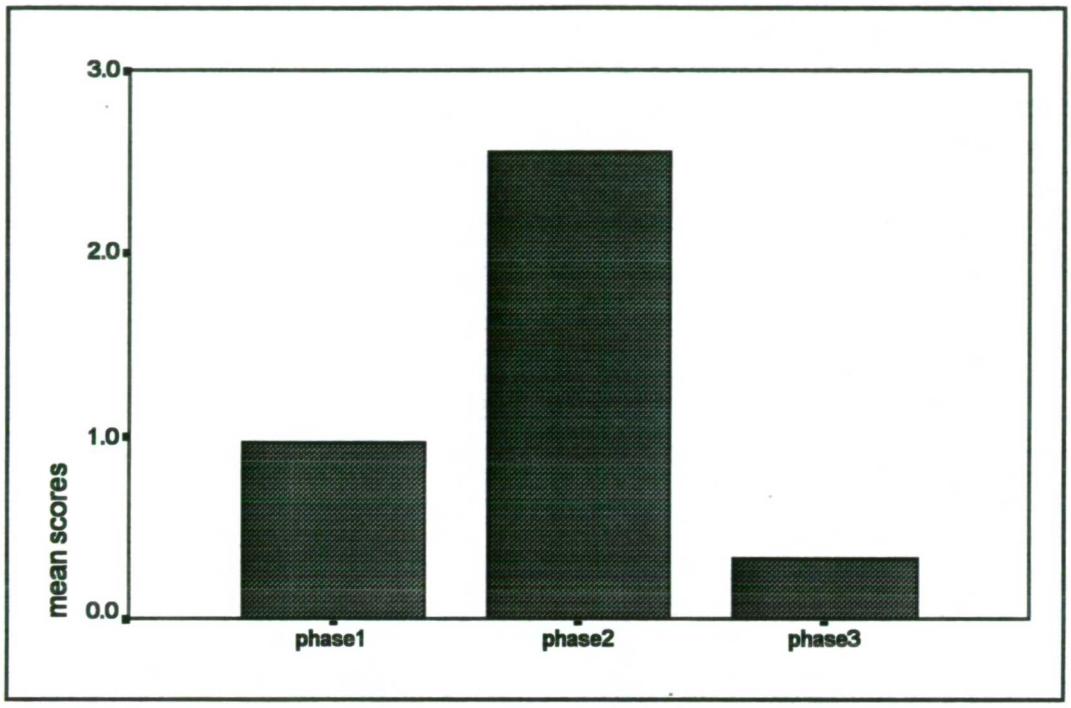


Figure 6.1 Observed distress behaviour: the three phases (N=53)

Each of the 53 children was observed during a routine blood test. More distress behaviours were shown during the *treatment phase* (phase 2) than during the *anticipation phase* (phase1) or the *recovery phase* (phase 3) that is when the needle penetrated the skin, the blood was drawn out and the sensitive area dabbed with a sterile cotton bud.

Table 6.3 Describing the relationship between the three phases and the observed distress behaviour (N=53)

the three phases	behaviour subtotals^	minimum	maximum^	mean^	*SD*^
1) Anticipation	51.14	0	10.88	0.96	1.85
2) Treatment	135.66	0	18.75	2.56	3.44
3) Recovery	17.91	0	3. 00	0.34	0.61
total distress	204.71	0	22.38	3.86	5.19

^ the weighted distress behaviour scores before the log transformation

The children who displayed more distress behaviour in the first phase also showed more in the second and third phase. *Internal consistency* between the three phases was tested using Pearson's product-moment test and significant correlations were found between the anticipation phase and the treatment phase (r=.53, p<.001, N=53) and the treatment phase and the recovery phase (r =.78, p<.001, N=53). Internal consistency was therefore established. The distress behaviour scores for all seven distress behaviours of the three phases were combined to make up *total distress behaviour.*

The total distress behaviour score as measured by the OSBD will be used to explore the relationship between observed distress behaviour and self-reported distress (Kidcope) during the blood test (first reported in Section 5.10). Furthermore, the seven distress behaviour scores (Figure 6.2) and the total distress behaviour score as recorded on the OSBD will be compared with the coping behaviour *active interest.* The distress and coping behaviours for each child were observed simultaneously during the blood test.

6.5.2 The seven behaviour categories

The total behaviour mean scores before the natural log transformation are illustrated by Figure 6.2. The *Restraint* category was used more than any of the others. This is possibly due to the nature of this medical procedure. The body and especially the arm, from which the blood is taken, were held down when children were particularly agitated. Anxious parents restrained the children and kept them still to ensure quick and safe completion of the blood test.

The children were also found to *Cry*, and once started it was difficult for the medical professional or the parents to stop the flow of tears. Patients who cried during a routine blood test reported harbouring a strong dislike for the procedure. Jay *et al.* (1983) found overall distress behaviour reached a plateau in children between the ages of 6 and 7 years.

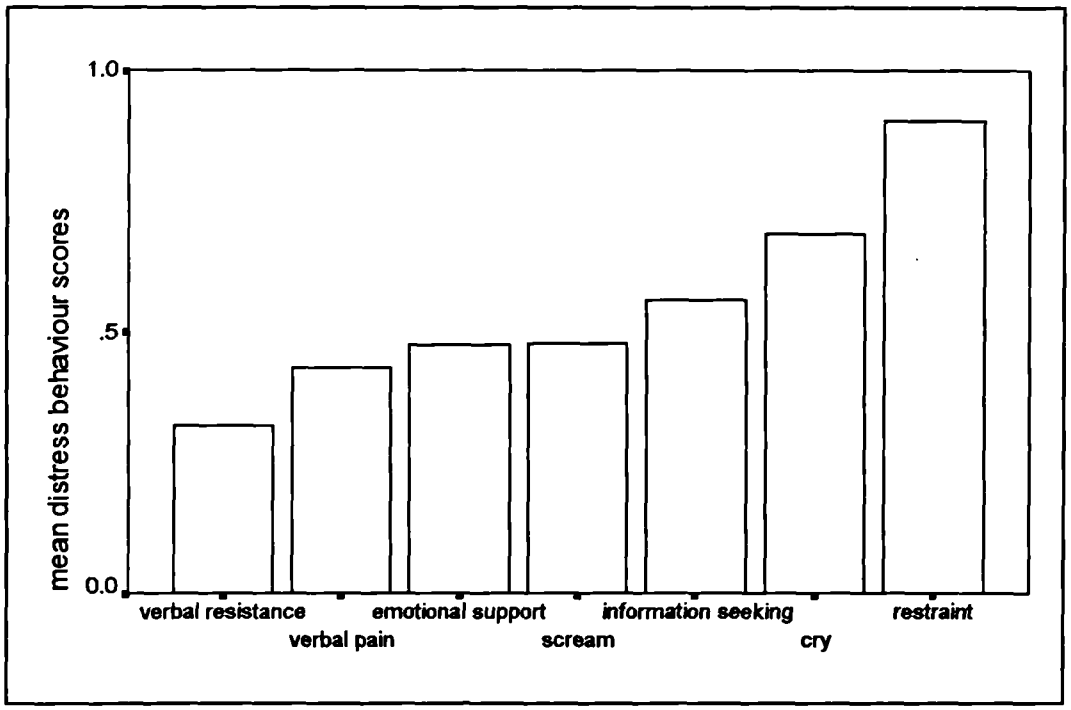


Figure 6.2 Observed distress: the seven behaviour categories

The distress behaviours, with the exception of *Information Seeking*, are associated to various degrees (Table 6.4). Pearson's correlation was applied and the results from r=.35 to r=.56, N=53, explaining up to 32% of the variance. This indicates reasonable consistency between the six behaviour categories.

Table 6.4 Correlation coefficients: intercorrelations between the distress behaviours (N=53)

distress behaviour	1	2	3	4	5	6	7
1 Information Seeking	-						
	-						
2 Cry	r=-.11	-					
	p=.415	-					
3 Scream	r=-.04	r=.51	-				
	p=.772	p<.001	-				
4 Restraint	r=-.05	r=.50	r=.50	-			
	p=.735	p<.001	p=<.001	-			
5 Verbal Resistance	r=-03	r=.39	r=.43	r=.36	-		
	p=.831	p=.004	p=.001	p=.008	-		
6 Emotional Support	r=-17	r=.41	r=.27	r=.44	r=.35	-	
	p=.216	p=.003	p=.055	p=.001	p=.011	-	
7 Verbal Pain	r=.18	r=.51	r=.56	r=.55	r=.47	r=.42	-
	p=.203	p<.001	p<.001	p<.001	p<.001	p=.002	-

As reported in Table 6.4 *Information Seeking* which is defined as 'any questions regarding medical procedures' such as "When will you stop?", "Is the needle in?" or "Is the blood coming out?" sets itself apart from the other behaviours. For example *Verbal Pain* is concerned with 'any words, phrases or statements which refer to pain, damage or being hurt', *Cry* 'crying sounds and/or onset of tears' or *Restraint* where

the patient 'must be physically held down by a member of staff or a parent with noticeable pressure and/or the child must be exerting force, and resistance in response to restraining attempts'. It might therefore be argued that Information Seeking is a distress behaviour different from the other six in so far as it is *about* or *concerned with* the medical procedure in question, whereas the others *stem from* or *are a reaction to* the medical procedure.

The behaviours during the three phases showed internal consistency and six out of seven distress behaviour categories showed some intercorrelations. It can therefore be assumed that reasonable stability exists between the behaviours. The scores were added to make up the total distress behaviour score. Thus, having considered children's distress behaviour during a routine blood test, the self-reported distress scores from the one-to-one interviews will be compared with the distress measured through systematic observations.

6.6 Validating the distress element of the Kidcope Checklist

Referring back to the blood test, which the researcher observed earlier and while completing the Kidcope Checklist, the patients reported on three distress factors: nervous/anxious, sad/unhappy and cross/angry. The distress behaviour scores recorded during a routine blood test and reported in Section 6.5.1 (*observations*) and the self-reported distress scores referring to the blood test and reported in Section 5.10 (*interviews*) were correlated in an attempt to validate, for the first time, the distress element of the Kidcope Checklist (Pretzlik & Sylva, 1995). These findings not only establish the validity of the distress element but they also strengthen the validity of the OSBD reported in Elliott *et al.* (1987).

It was found that children who rated themselves as feeling more distressed during the blood test had also displayed more distress behaviour during the same medical procedure (r=.56, p<.001, N=53). This welcome association shows that children rate

themselves along a distress continuum in much the same way as the researcher measured them on the OSBD. The similarity between these seriously ill children's self-reported distress and their OSBD shows them to have an ability to communicate their feelings during a one-to-one self-report interview using the distress element of Kidcope. This result, confirming the fact that children are capable of reporting their distress, might be taken to imply that their concerns and self-assessment related to pain and medical treatment should be taken seriously both by researchers and by medical teams.

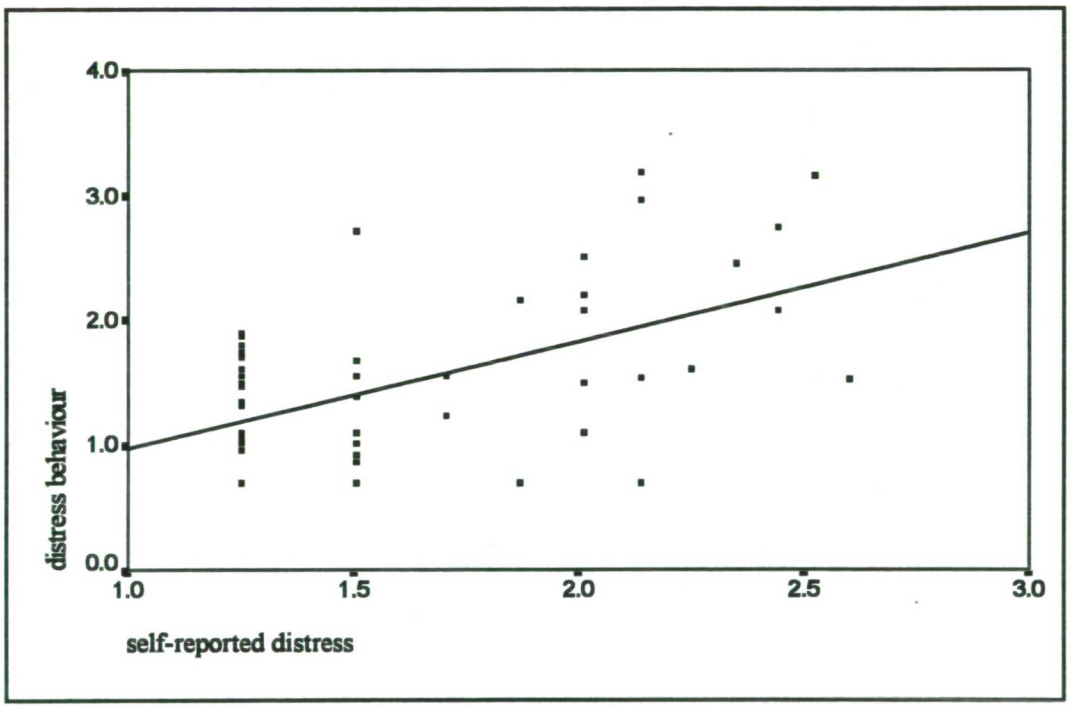


Figure 6.3 Distress during a routine blood test: the relationship between the children's self-reported distress and their distress behaviour observed by the researcher

Figure 6.3 illustrates the association between the two distress measures. For the benefit of the scattergram, the data for both the distress behaviour and the self-reported distress were adjusted by using a natural log transformation.

6.7 Comparing coping behaviours with distress behaviours and self-reported distress

Observing the children's distress behaviour provided an excellent opportunity to assess their involvement in the medical procedure. During the treatment phase of the blood test the child either observed closely, i.e. showed *active interest* or he or she avoided getting involved, i.e. showed no interest in the procedure. These coping behaviours were measured for their presence or absence during four continuous 15 second intervals giving a possible range of 0 to 4. The data were not Normally distributed, but fell into two behavioural categories: *actively interested* (n=23) and *not interested* (n=30) copers.

These two subgroups of copers were looked at in the light of distress behaviour and self-reported distress. Differences between the two groups and distress were found.

6.7.1 Differences between coping behaviour and distress behaviour

Children in the *taking no interest* coping behaviour group, with the exception of Information Seeking, displayed more distress related behaviour than children in the *taking an active interest* coping behaviour group. Using mean scores the behaviours and differences between the two patient groups are illustrated by Figure 6.4.

Paediatric patients who displayed active coping behaviour during the blood test displayed less distress behaviour than children with avoidant coping behaviour. *Active* copers cried less, were less often held down, complained less, sought less physical or verbal comfort and spoke less often about pain and discomfort.

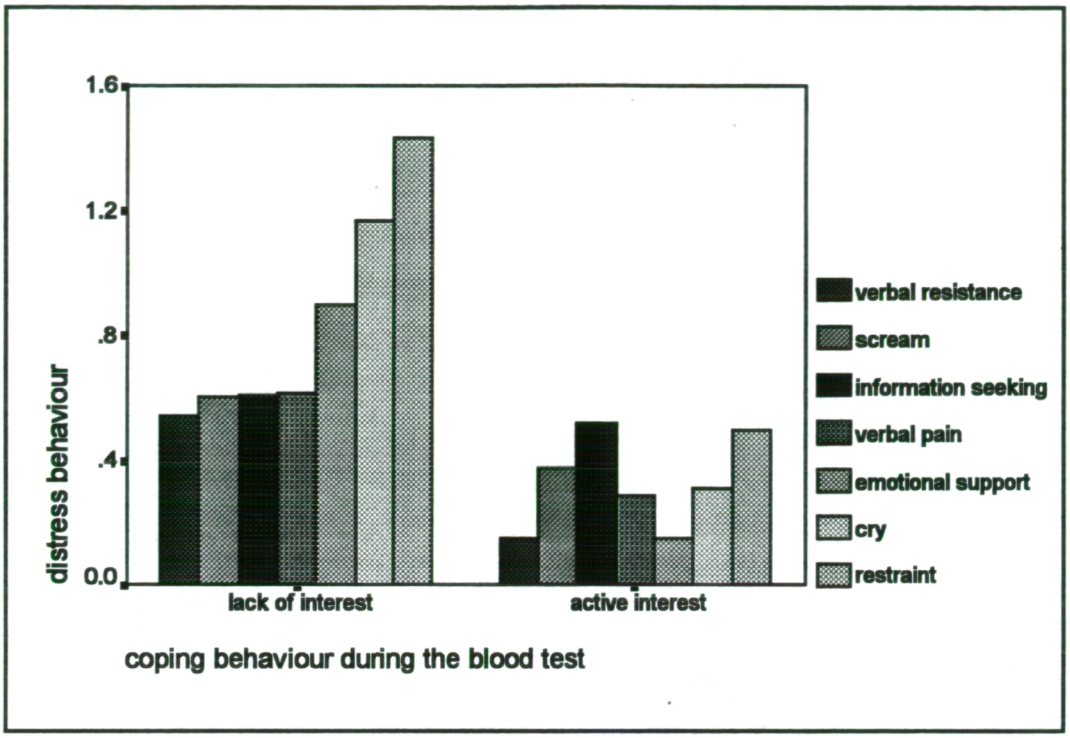


Figure 6.4 Distress behaviour: interested (n=23) and non interested (n=30) copers

A multivariate analysis of variance was employed to compare the mean scores of the distress behaviours (within-subjects) with the coping behaviours (between-subjects). The variable *distress behaviour* has seven factors and the variable *coping behaviour* is made up of two factors. The between-subject effect $F(1,51)=7.76$, $p=.007$ confirms an overall difference between the distress behaviour and the two types of copers. Children who took an active interest in the procedure showed less distress behaviour. The Mauchly test for sphericity involving behaviour within-subject effect was significant ($p<.003$) and it was therefore necessary to adjust the degree of freedom using Greenhouse-Geisser Epsilon. No significant difference between the distress behaviours was found $F(4.53, 230.79)=1.30$, $p=.257$ and overall interaction involving distress behaviour by coping behaviour was not established $F(4.53, 230.79)=1.37$, $p=.240$.

When further exploring the data of the distress behaviour and the coping behaviour, it was found that not all patients had shown distress behaviour in each of the seven behaviour categories. Thus, the distress behaviour data were dichotomised into two groups, the children who showed *some* distress and the children who showed *no* distress. This was done for all seven behaviour categories and the results are presented in Table 6.5.

Table 6.5 Differences between observed distress behaviour and the avoidant and active copers

behaviour	lack of interest distress behaviour YES %	NO %	active interest distress behaviour YES %	NO %	Yates χ^2	effect size	*p*-value
Information Seeking	52.2	47.8	56.7	43.3	0.02	. 04	. 745
Cry	34.8	65.2	10. 0	90. 0	4.86	. 31	. 027*
Scream	30.5	69.5	16.7	83.3	1.41	. 16	. 235
Restraint	34.8	65.2	16.7	83.3	2.31	. 21	. 129
Verbal Resistance	47.8	52.2	16.7	83.3	5.99	. 32	. 014*
Emotional Support	56.6	43.4	13.3	86.7	9.25	. 42	.001*
Verbal Pain	34.8	65.2	16.7	83.3	2.31	. 21	.129

* statistically significant differences between the two groups at $p<.05$

The analysis consists of behaviour and non behaviour for copers both actively interested as well as lacking interest during the blood test. A 2x2 cross tabulation was used providing information about relationships between the variables. Yates' correlation for continuity was applied and three behaviours show significant differences between the two groups. Children who cried more, showed more verbal resistance and needed more emotional support showed little interest in the blood test.

When Figure 6.4 is inspected, differences in distress behaviour can be seen. The mean scores of the distress behaviours represent the dichotomised bars and the multivariate analysis of variance. On the other hand, Table 6.5 presents the behaviour as well as the non-behaviour scores rather than the mean scores and takes into account the differences between the distress behaviour and the coping behaviour. When inspecting the results in Table 6.5, the differences appear to be less robust than first thought. This result is possibly due to non-behaviours which were recorded during the observations.

A logistic regression was used to examine the overall relationship between all seven distress behaviours and the two coping behaviours. A logistic regression is similar to a linear regression, except that the dependent variable (coping behaviour) is a dichotomy. Once *Emotional Support* had been taken into account as a significant predictor ($\chi^2(1)=11.46, p<.001$), none of the other six distress behaviours, including *Crying* and *Verbal Resistance,* were significant.

6.7.2 Differences between coping behaviour and self-reported distress

The trend continues where children who showed an active interest in the blood test were less distressed. The Kidcope self-reported distress scores for the blood test scenarios and children's *active interest* coping behaviour were compared. The differences are illustrate by Figure 6.5. The children who took an active interest in the blood test also reported having felt less distressed during the procedure.

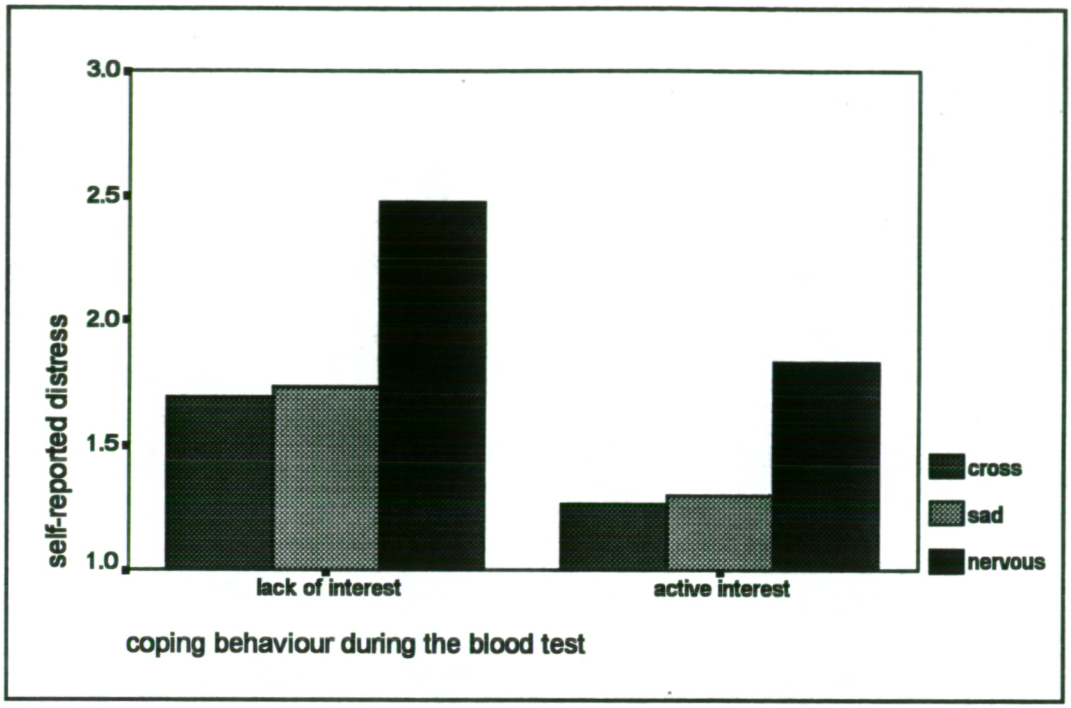


Figure 6.5 Self-reported distress: interested and non interested copers

The Mann-Whitney U test for two independent samples was applied to evaluate differences between the children showing an active interest and the children showing no interest in the blood test. The three factors were: nervous/anxious (U=274.5, p=.20, n=23, n=30), sad/unhappy (U=269.5, p=.10, n=23, n=30) and avoidant children, i.e. those children who did not visibly get involved in the blood test procedure, reported feeling significantly more cross/angry then active children (U=259.0, p=.05, n=23, n=30).

6.8 A summary of the results

Having observed each child during a stressful situation and having referred him or her back to that real-life stressor during a one-to-one interview, it was found that children who exhibited more distress behaviour also reported feeling more distressed. An

association between self-reported distress and distress behaviour was established. Not only does this result for the first time validate the Kidcope distress element and strengthen OSBD's validity, it also suggests, that when children describe how they feel or have felt during a medical procedure, they should be listened to.

The children who took an active interest in the blood test were less distressed than those who took no interest. The results are clear and should be of concern although it is still too early to generalise. It may be that the children who take an active interest are children not worried by a venipuncture in the first place, on the other hand, it may be that they take an interest to distract themselves during the procedure. The established differences between the children who took an active interest in the medical procedure and the children who showed no interest should be subject to further investigation in future studies. Repeated observation of the same medical procedure, i.e. blood tests, or a combination of medical procedures, would then validate this coping measure.

In both this and the previous chapter the self-reported coping and distress and the observed coping and distress were discussed. In the next three chapters these results, called the core of coping in this thesis, will be taken further. That is to say, the children's way of coping as assessed here will be looked at and related to factors such as individual differences, parental coping and the social environment of the family. Study 4 begins by considering the children's competence and feelings of self-worth.

CHAPTER SEVEN

CHILDREN'S INDIVIDUAL DIFFERENCES AND COPING INCLUDING THEIR PERCEPTION OF COMPETENCE AND SELF-WORTH

Study 4

The results discussed in the next three chapters are based on data from the one group of children and their parents. An attempt will be made to understand the origins of the differences in coping reported so far. The analyses will look at the children's individual differences, parental variables and the family climate. A limitation of these variables is that they have been collected 'after the fact' - i.e. after illness and treatment onset. It won't be possible, therefore, to know whether these factors predate the children's behaviour and subjective processes. However, what will be provided is an exploration of the social cognitive structure of these children and its background.

Relationships between children's individual differences and their coping processes, coping behaviours, self-reported distress and distress behaviours are reported in this chapter. Four factors; the children's perception of their competence and self-worth, their age, sex and experience make up what is here called *individual differences.* It is these individual differences and their possible influence on the way children cope with a serious illness that are under investigation.

Information was recorded about the age of each child, whether boy or girl and how long ago the illness was first diagnosed. During a one-to-one interview with the same researcher all 53 children reported how they felt about themselves. Details concerning the Self-Perception Profile for Children (SPPC) measure and its application are discussed first, then followed by results in the second part of this chapter.

Research questions:

> Is there a relationship between children's coping strategies reported in Kidcope and their perceived competence and self-worth as measured by the Self-Perception Profile for Children?
>
> Is there a relationship between children's coping behaviours and their perception of competence and self-worth?
>
> Is there a relationship between children's self-reported distress in Kidcope and their perception of competence and self-worth?
>
> Is there a relationship between children's distress behaviour during the blood test (OSBD) and their perception of competence and self-worth?
>
> Is there a relationship between children's coping strategies reported in Kidcope and their age, sex and experience?
>
> Is there a relationship between children's coping behaviours and their age, sex and experience?
>
> Is there a relationship between children's self-reported distress on Kidcope and their age, sex and experience?
>
> Is there a relationship between children's distress behaviour during the blood test (OSBD) and their age, sex and experience?

The factors which form the core of coping, and are discussed in this chapter, were reported in Chapter 5 (coping and distress *interviews*) and Chapter 6 (coping and distress *observations*).

METHOD

7.1 The Self-Perception Profile for Children: a self-report instrument

As children develop their identities and formulate concepts about the self, they assign positive and negative values to themselves. Collectively these self-evaluations

constitute the children's perception of their own worth. Asking them questions about how much they like themselves and how they rate their abilities is a procedure fraught with problems of biased responding. Children may not admit to their undesirable qualities, or, more seriously, they may be aware of qualities which they believe others consider socially undesirable. The Self-Perception Profile for Children (Harter, 1985) used in this study was designed to reduce this bias.

The original measure (Harter, 1982) and the revised version (Harter, 1985) were developed to elicit children's *domain specific* judgements of their competence, as well as a *global perception of their worth* or esteem as a person. Four separate subscales emerged from the interviews and observations with a large cross section of children. The Perceived Competence Scale for Children questionnaire (PCSC) tapped the three competence domains, and self-worth: *cognitive, social* and *physical*, plus *global self-worth.* A separate score was produced for each of the four components. The score provides measures of perceived competence in the three domain areas and an independent assessment of the child's perception of self-worth. The original instrument measuring self-esteem was designed for children between the ages of 8 and 18. According to Susan Harter, by the age of eight children not only make discrete judgements about their competence in different domains, but by then they have also constructed a view of their general self-worth as a person - over and above the specific competence judgement. The three measures for different age groups, briefly discussed below, have been generated from the Perceived Competence Scale for Children (Harter, 1982).

The instrument designed to assess younger children's perception of their competence (4-7 years), the Pictorial Scale of Perceived Competence and Social Acceptance for Younger Children (PSPCSA), is based on and was developed from the version for older children (PCSC). The questions which make up the PCDC were replaced by pictorial questions, one set for boys and one set for girls. The younger group of children, according to Harter and Pike (1984), responded eagerly to this format, showing an understanding of these age appropriate items. The psychometric

properties of the scale are reported to be valid and reliable. Although some of the children in the present study were not yet eight years old, it was decided that the Self-Perception Profile for Children was suitable (for rationale and pilot work on the SPPC questionnaire see Section 4.2.4).

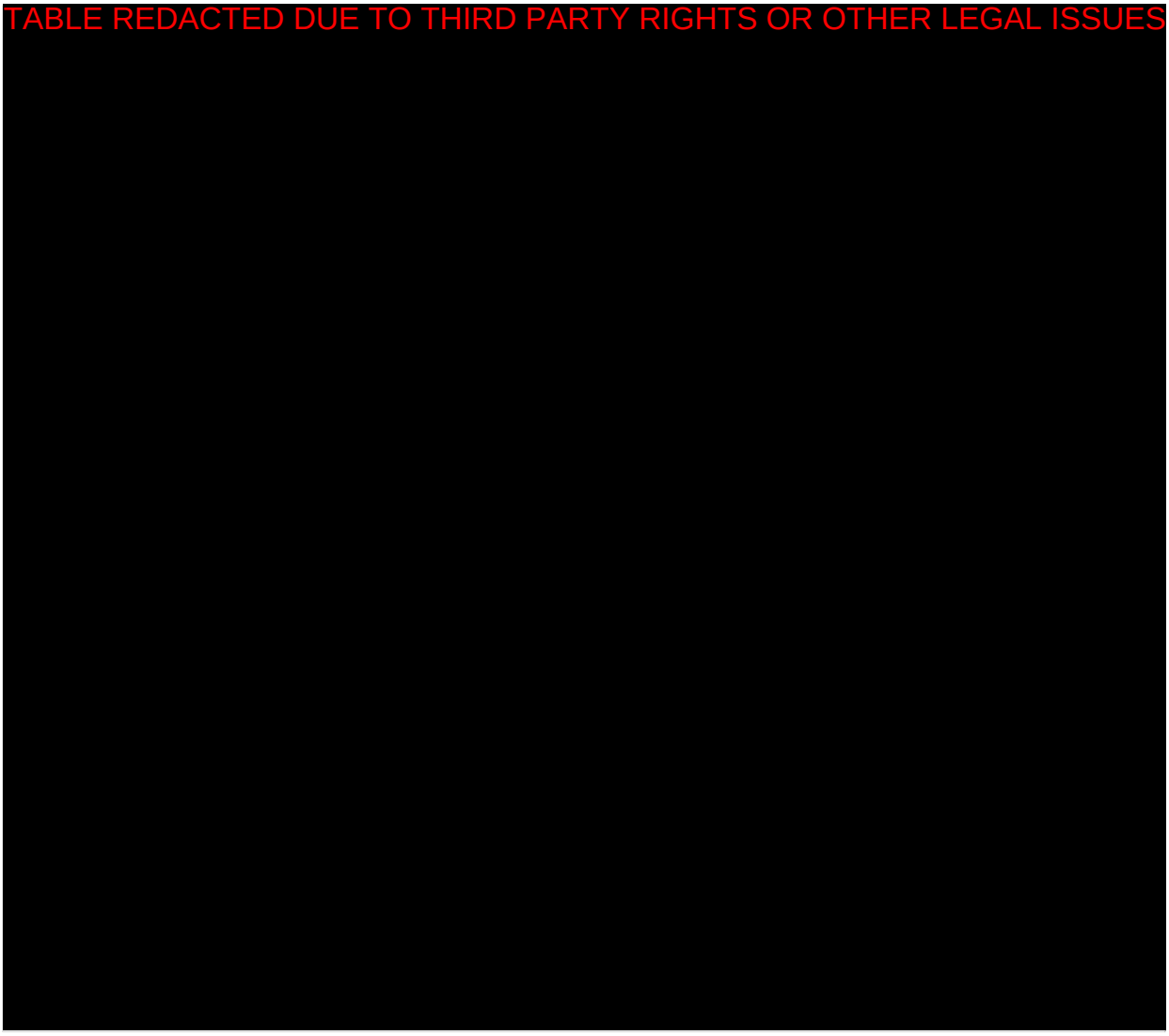
Susan Harter originally used the questionnaire with children as well as with groups of teenagers. The Self-Perception Profile for Adolescents (SPAA, 1988) was later developed as a more appropriate measure and is based on the Self-Perception Profile for Children (1985) version. Some adjustments have been made, for example the phrase 'some *kids*' has been replaced by 'some *teenagers*'. Three additional domains reflecting particular concerns of adolescents have been added; these are: *job competence, close friendship* and *romantic appeal.* Although some adolescents both male and female took part in this study, it was decided that the Self-Perception for Children (1985) version was the appropriate measure for all children (for rationale see Section 4.2.4).

As mentioned already, unlike the structure used by other researchers, for example Coopersmith (1967), the conceptual approach to the assessment of competence and self-worth as used in this study is *domain specific.* Harter assumes that children see themselves differently in every domain and expects them to make meaningful judgements when completing the questionnaire. Support for this assumption has been obtained from a large sample of children and adolescents (Harter & Pike, 1984). While developing the Self-Perception Profile for Children it was found that children are able to differentiate between the five domains and their general self-worth as a person. It was this revised version that was completed by all 53 children who took part in the main study, and will now be discussed. (Appendix VI)

Two more domains were added to the original four, they are *Physical Appearance* and *Behavioural Conduct.* Besides extending these subscales, several domain-specific and global self-worth items underwent improvement. Children's perception of five specific domains, *Scholastic Competence, Social Acceptance, Athletic*

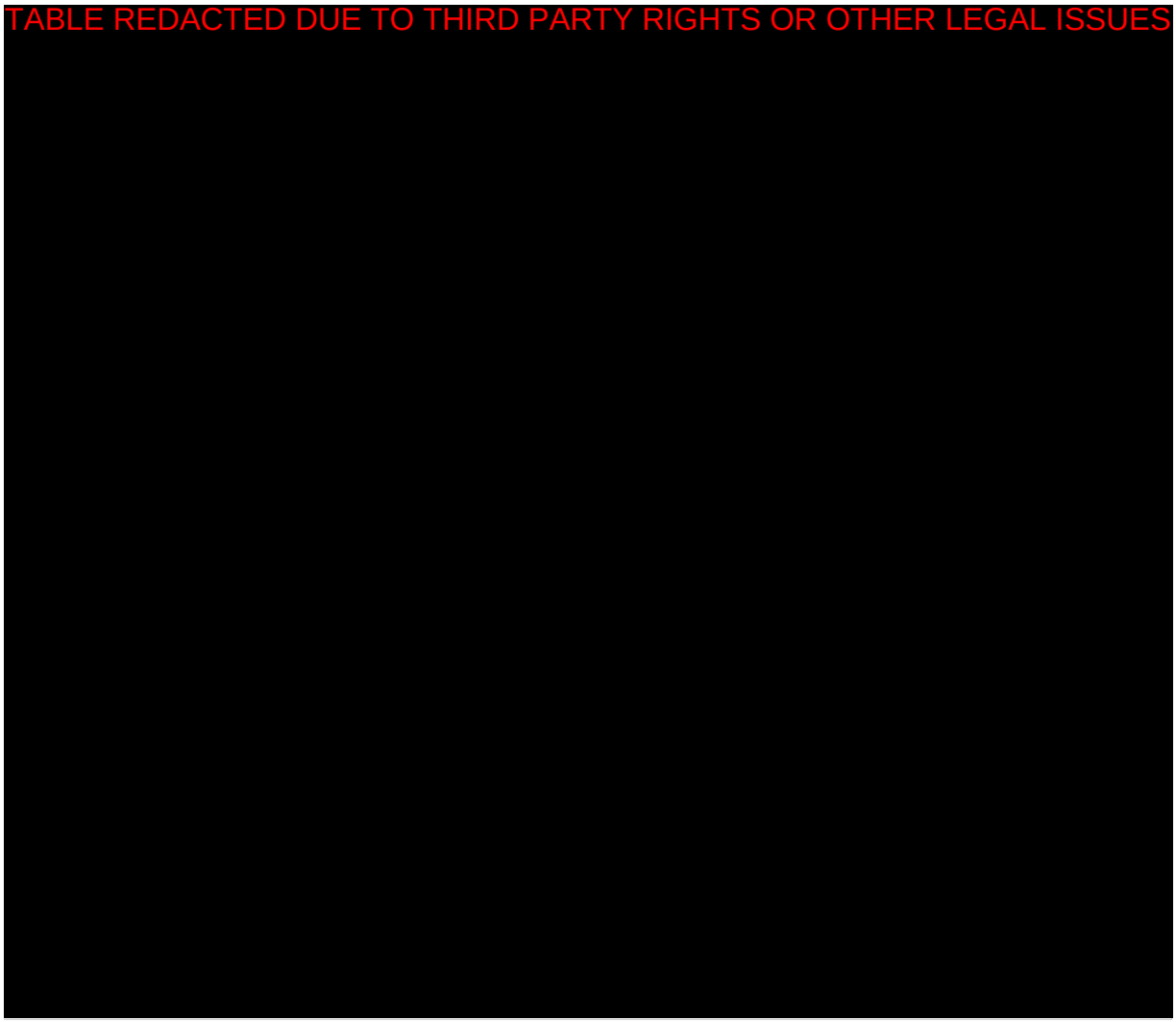
Competence, Physical Appearance and *Behavioural Conduct* is measured. In addition to these five domains a global judgment, *Global Self-worth*, is assessed by the SPPC independently, and supports the notion that children do not feel equally competent in every domain.

Table 7.1 Self-Perception Profile for Children: the five domains and Global Self-worth (Harter, 1985)



Children's perception of self-esteem is looked at both directly, through Global Self-worth and indirectly through their domain specific judgements. It is important to note that the Global Self-worth subscale is not a measure of general self competence. Global Self-worth is assessed separately and independently of the five specific competence domains. Through this independent assessment, the relationship between Global Self-worth and the five domain-specific perceptions of competence can be looked at.

Table 7.2 The six subscales (Harter, 1985)



7.1.1 Validity of the SPPC

Face validity and *meaningfulness* of the items presented to the children were calculated from 300 one-to-one interviews. The data from these interviews helped to construct the scale initially. Research involving large samples of school children contributed to the development of a robust test assessing children's positive and negative values about themselves. As the SPPC (Harter, 1985) is based on and extended from the PCSC (Harter, 1982), validity and reliability of the scale discussed below were established using data from research on the original and the revised version. Five studies contributed to the validity and reliability of the scale described by Harter (1982). The questionnaire was administered to groups of equal numbers of boys and girls - first, 133 children aged 9-12, second, 341 children aged 8-11 years and a third study included 741 children aged 8-11 years; the fourth and fifth studies included 470 children aged 8-12 and 746 children aged 8-14.

What does Susan Harter's SPPC questionnaire set out to measure and *how well* does it do it? Ten questions for each of the four subscales make up 40 items in all. The children answered questions relating to four domains (*cognitive* is school competence; *social* is peer related; *physical* is associated with skills at sports and outdoor games and *general* self-worth). Further factor analysis showed that a four-factor solution at the time was the most appropriate method from both the point of view of looking at the statistical results and from the way the items were interpreted and understood. Four assigned items were excluded due to insufficient variability and internal consistency so that 36 items made up the final four domains of the PCSC.

A 28 item scale, comparable to items answered by their pupils, was completed by two groups of teachers (n=28 and n=16). A factor pattern with the loadings of .84, .74, .94 and .93 on the four domain specific factors showed significant agreement between the children's perceived and reported self-esteem and the teachers' report of the same.

7.1.2 Reliability of the SPPC

The *consistency* and *stability* of any psychometric instrument are of interest to the researcher. Subscale reliability was assessed and internal consistency established (α range from .73 to .83 for the cognitive, social, physical and general subscales). A sample of 208 children took part in a test-retest reliability study (Harter, 1982). The pupils were retested after 3 months and significant correlations were found (r=.78, r=.80, r=.87 and r=.70). Another group of 810 children were retested after 9 months with the following results: r=.78, r=.75, r=.80 and r=.69. These data show clear reliability scores. However, if as was suggested by Harter (1983), children's perception of their competence and their self-worth is closely related to their age and developmental level then these results, establishing stability of the self-perception scale over a longer period of time, should be treated with care.

Mean scores from four sample groups were stable across subscales and age. Intercorrelations among subscales were also reported to be high, as were teacher ratings and the internal consistency reliability for the same four subscales (r=.96, r=.93, r=.94 and r=.93) which explained between 87% and 92% of the variance. However, as the SPPD has been expressly designed to assess *the child*'s perception of competence and feeling of self-worth, results related to validity involving such measures as teacher ratings or achievement tests should be looked at with caution.

Overall the instrument was reported to have been widely tested on large groups of American school children. It measures what it set out to measure and has been shown to be reliable, both internally and across time. An example of the SPPC is included in Appendix VI

7.2 Self-Perception Profile for Children: the procedure

The application and the scoring of the SPPC used in this study will now be discussed. All data were collected by the same researcher during one-to-one interviews in the hospital environment. The SPPC checklist was completed by each child during the second contact session. The first contact session had been set up and carried out to enable each patient and the researcher to get to know each other informally on the hospital ward.

At the beginning of each interview the children were told that the researcher was trying to find out what sort of a person they were. It was stressed they were not being asked to complete a 'test'. There was no right or wrong answer and since all children are different from each other they were expected to give different answers to the questions. The researcher then explained how the question statements were set out and how they were to be answered. The sample statement provided on top of each scale was used as a first attempt and to clarify any queries which might have occurred at the outset.

SAMPLE STATEMENT

Some kids would rather play outdoors in their spare time		BUT	*Other kids would rather watch TV*	
Really true for me	**Sort of true for me**		**Sort of true for me**	**Really true for me**

Each interview took place in a quiet area in the hospital away from other children, parents and staff, thereby avoiding interruptions and the potential influence of social desirability. The instructions and items were read to the patient and the questionnaires were completed in an interactive style. Those items the children did not clearly understand were discussed and explained. The children were given a choice of ticking the appropriate boxes themselves or having the researcher do it.

After filling in the date and name of the child, the sample statement at the beginning of the scale was read out and completed, then followed by 36 statements structured and answered in the same way.

7.2.1 The scale structure

The SPPC scale is entitled *What am I like*? An example is included in the appendix. Each of the six subscales (Tables 7.1 and 7.2) contains six statements, making a total of 36 statements. Within each subscale half of the statements are worded so that the first half reflect a low score and the other half a high score and vice versa; in other words, the order and therefore the weighting is randomly alternated.

7.2.2 The question format

From hearing or reading each of the statements, the child was required to indicate what sort of a person he or she perceived him or herself to be. The part-statement on the left, for example, says *Some kids often forget what they learn* and the part-statement on the right *Other kids can remember things easily.* After each child indicated the answer most like themselves, they were then asked whether this was *Really true for me* or *Sort of true for me.*

Each question was ticked in the appropriate box and scored on a 4 point Likert-type scale:

from 1 suggesting low perceived competence or Global Self-worth
to 4 suggesting high perceived competence or Global Self-worth

The range for each statement is 1- 4 and the possible range for each subscale is 6-24. The mean scores of the six subscales were used and will be assessed in Section 7.4.

This question format not only provides a 4 point ordinal data record of a child's feelings of competence and self-worth but also effectively reduces a child's tendency to give socially desirable responses (Harter, 1985).

Each subscale score and their mean scores are reported as six separate results, independent of each other. Harter (1982) says that although the data was ordinal, both the statement and subscale distributions were normal making parametric statistical analyses appropriate.

7.3 Individual differences: coping in children with a serious illness

In this study the individual differences of the children are made up of four components: *self-esteem* which was assessed through self-report methods, *age* which ranged from 84 to 194 months, *sex* distribution of 22 girls (42%) and 31 boys (58%) which was in accordance with the general population of patients with aplastic anaemia and leukaemia (Lilleyman, 1994), and *time since the illness was first diagnosed* which ranged from 2 to 67 months. The variation of experience is mainly due to the fact that some children were first time patients while others had relapsed after differing intervals of remission.

For a more detailed description of the sample see Section 4.1 and a summary of the composition of the sample is reported in Table 4.1.

RESULTS

Having focused on the core of coping in Chapters 5 and 6 a broader view is now taken to explore more general questions, questions about the possible association between coping and individual characteristics of the children.

All 53 children completed the Self-Perception Profile for Children scale (Harter, 1985). The self-esteem data are presented in the first part of this result section. The children's perceived feelings of self-esteem are described and relationships between the six subscales and coping were sought. The results will be reported in Section 7.4, associations between coping and self-esteem in Section 7.4.4.1 and between distress and self-esteem in Section 7.4.4.2. In the second part of the result section it is the children's age (Section 7.5), sex (Section 7.6) and experience (Section 7.7), which will be looked at and related to their self-reported coping strategies and observed coping as well as their self-reported distress and observed distress.

7.4 The Self-Perception Profile for Children: self-esteem and children's coping and distress

The 36 statements on the Self-Perception Profile for Children scale are answered on a 1 to 4 Likert-type scale and six items make up a domain or subscale, giving a possible range of 6-24. The subscales are divided into five domains and global self-worth. Although in this study as in previous work reported by Harter (1982, 1985) the rating scale is ordinal, parametric analyses were used. Harter found both the statement-items and the subscales to be Normally distributed. Inspection of the distribution of the statement-items and subscale scores in this study also showed the data to be Normally distributed and it was decided to use statistical techniques for parametric data.

A word of caution should be added here, Harter (1982, 1985) warns that her scale has been used mainly with 'normal' populations, that is to say with healthy groups of school children with more or less stable family backgrounds. The children who took part in this study are considered a special group and it will therefore be of interest both in terms of the robustness of the measure and in terms of the 'normality' of the sample if results are comparable to previous findings.

7.4.1 The six subscales

The SPPC rating scale is made up of six subscales; five domains and Global Self-worth.

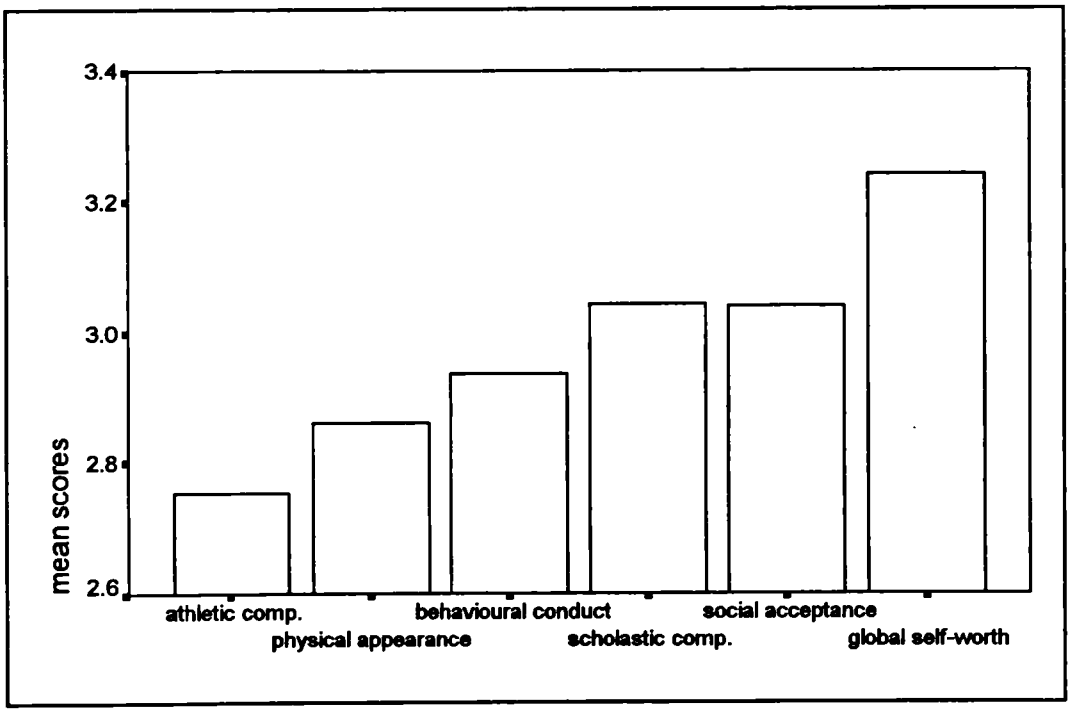


Figure 7.1 The Self-Perception Profile for Children: the six subscales (N=53)

The mean values for the whole group of the six subscales are illustrated by Figure 7.1. The variation between overall mean scores is limited and ranges from 2.76 for *Athletic Competence* to 3.24 for *Global Self-worth.*

Table 7.3 Describing the five domains and Global Self-worth (N=53)

subscales	minimum	maximum	mean	*SD*
Scholastic Competence	1.33	4. 00	3.04	0.61
Social Acceptance	1.33	4. 00	3.04	0.71
Athletic Competence	1.17	4. 00	2.76	0.71
Physical Appearance	1. 00	4. 00	2.86	0.81
Behaviour Conduct	1.67	4. 00	2.94	0.56
Global Self-worth	2. 00	4. 00	3.24	0.58

The scores reported here are more or less in accordance with results reported by Harter (1982). A large group of healthy children (N=341) completed the scale. Mean scores in her study were found to be between 2.5 and 3.2 and compare with mean scores in the present study which, as Table 7.3 illustrates, are only slightly higher, between 2.8 and 3.2. These mean scores fall above the midpoint and indicate neither ceiling nor floor effect. Standard deviations are all below 1 demonstrating a small yet adequate amount of variance.

7.4.2 Five domains and their relationship with Global Self-worth

The relationships between the five domains and Global Self-worth were tested using Pearson's product-moment and some links established. The results are reported in Table 7.4.

Table 7.4 Correlation coefficients: intercorrelations between the subscales (N=53)

subscales	1	2	3	4	5	6
1 Scholastic	-					
Competence	-					
2 Social	r=.27	-				
Acceptance	p=.049	-				
3 Athletic	r=.33	r=.51	-			
Competence	p=.014	p<.001	-			
4 Physical	r=.21	r=.35	r=.33	-		
Appearance	p=.138	p=.010	p=.016	-		
5 Behavioural	r=.48	r=.23	r=.27	r=.44	-	
Conduct	p<.001	p=.105	p=.053	p=.001	-	
6 Global	r=.35	r=.28	r=.31	r =.66	r=.51	-
Self-worth	p=.011	p=.046	p=.023	p<.001	p<.001	-

The six subscales are related to each other to varying degrees and while there are sample variations, there are also several common patterns. For example, the children who felt they usually behave well reported doing well at school, the children who reported being good at sport have many friends and those who reported liking the way they look felt good about themselves in a global sense.

Each of the five domains is related to *Global Self-worth,* although some contributed more than others to children's perception of self-worth. The correlation coefficients ranged from r=.28 explaining 9% of the variance for Social Acceptance to r=.66 explaining 44% of the variance for Physical Appearance. The children who reported feeling good about the way they look and the way they behave generally feel good about themselves.

These results are comparable with Harter's (1985, cited in Harter 1987) findings. Based on a large sample (N=1543) she reported similar correlations between Global Self-worth and the five domains: *Physical Appearance* (r=.66), *Social Acceptance* (r=.36), *Scholastic Competence* (r=.35), *Athletic Competence* (r=.33) and *Behavioural Conduct* (r=.30). In this British sample of children with leukaemia or aplastic anaemia only *Behaviour Conduct* (r=.51) ranked higher. Both the healthy American children and the British children with a serious illness reported *Physical Appearance* as the most important contributor to their perceived feeling of *Global Self-worth.*

Although it is not possible to generalise with a small sample (N=53) of 'special' children, the overall pattern suggests these ill children have similar perceptions about themselves as do healthy children. The two most critical domains related to the general feeling of self-worth involve how good the children think they look and how well they think they behave both in the school and the home setting.

7.4.3 The five domains and Global Self-worth: children's self-reported coping and coping behaviour

Data on the children's way of coping were collected through one-to-one interviews. The Kidcope Checklist was completed three times by each of them. The checklist was related twice to the children's chosen stressors in the common and illness context and once to a specific medical procedure, the blood test. The method (Sections 5.1 and 5.2), procedure (Section 5.3) and results (Sections 5.4, 5.5 and 5.10) relevant to this chapter are reported in Chapter 5.

The children's interest or involvement in the blood test was assessed. Each child was observed and their coping behaviour 'showing an active interest in the blood test' recorded. This coping behaviour was measured by its presence or absence during four continuous 15 second intervals in the treatment phase of the blood test. Recorded observations give a possible range of 0 to 4. The data were not Normally

distributed but dichotomous; the two groups are defined as *actively interested* (n=23) and *not interested* (n=30) copers. The method (Sections 6.2 and 6.3), procedure (Section 6.4.2) and results (Section 6.7) relevant to this chapter are reported in Chapter 6.

Section 7.4 looks in detail at the association between the children's coping (the coping strategies they reported to have used and their coping behaviour) and their perception of competence and feeling of self-worth.

7.4.3.1 Coping strategies and their competence and Global Self-worth

The total number of coping strategies reported to have been used by the children across three contexts (with a possible range of 0-10) and the five domains and global self-worth (with a possible range of 6-24) were correlated using Pearson's product-moment test. No significant relationships were found between coping and the way children felt about themselves. This result indicates that coping as measured by Kidcope is not associated with children's self-worth as measured by the Self-Perception Profile for Children.

7.4.3.2 Coping behaviour and their competence and Global Self-worth

Figure 7.3 illustrates clear differences between the way the children feel about themselves and how they behaved during the blood test. The children who took an active interest in the procedure, perceived themselves as feeling more competent with their school work, physically more attractive, and behaving better than the children who showed no interest in the blood test. The active copers' general feeling of self-worth is higher than the children who showed no interest in the blood test (Pretzlik & Sylva, 1996).

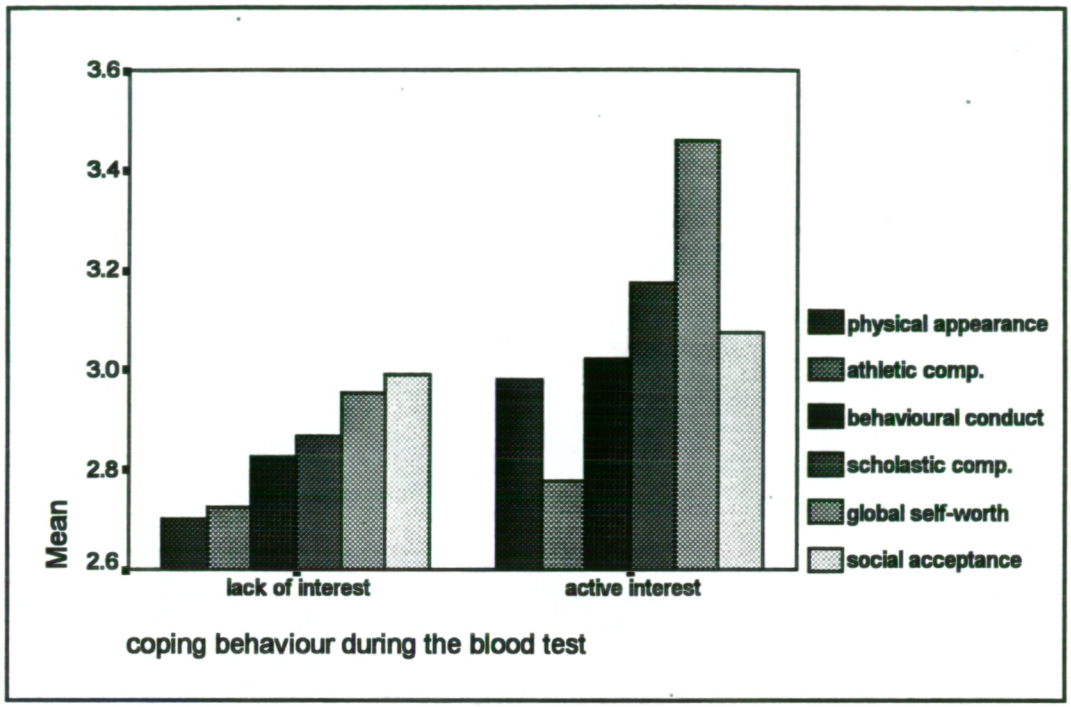


Figure 7.2 Children's coping behaviour during the blood test: the five domains and Global Self-worth (N=53)

Differences between the two types of copers are illustrated by Figure 7.2. A t-test was applied to establish statistically significant differences between the two groups. The results are reported in Table 7.5.

Table 7.5 Differences between perceived competence and Global Self-worth in the avoidant and active copers

subscales	lack of interest means (n=23)	active interest means (n=30)	*t* value df=51^	*p* value
Scholastic Competence	2.87	3.18	1.87	. 067
Social Acceptance	2.99	3.08	0.42	. 675
Athletic Competence	2.72	2.79	0.26	. 796
Physical Appearance	2.69	2.98	1.27	. 209
Behavioural Conduct	2.82	3.02	1.27	. 209
Global Self-worth	2.95	3.46	3.46	. 001

^ Levene's test for equality of variance was non significant (p>0.05) for all six domains, therefore equal variance was assumed (df=51)

Although a significant difference was found in only one domain, Global Self-worth, between the two groups of copers and the six subscales, the trend when looking at the mean scores shows active copers perceive themselves as having an overall feeling of higher self-esteem than avoidant copers. Although the mean scores for all six subscales were higher for the active coper group, it should be noted that the increases were only small.

A multivariate analysis of variance was used to compare the mean scores of the six subscales measuring children's perceived competence and Global Self-worth (within-subjects) with coping behaviour (between-subjects). The variable *self-esteem* is made up of six factors (the five domains and Global Self-worth) and the variable *coping behaviour* is made up of two factors (lack of interest and active interest). The between-subject effect was significant ($F(1,51)=3.74$, $p=.059$) suggesting overall differences between the children's perceived self-esteem and the two types of copers. The children who took an active interest during the treatment phase of the blood test reported feeling generally better about themselves. The test of Mauchly's sphericity

involving self-esteem within-subject effect was significant (p=.004) and it was therefore necessary to adjust the degree of freedom using the Greenhouse-Geisser Epsilon. This result indicates that the overall correlations between the six subscales show differences (Table 7.4). Significant differences within subjects between the six subscales of the Self-Perception Profile for Children rating scale were found F(4.08,207.85)=4.73, p=.001, but overall interaction involving self-esteem by coping behaviour was not established F(4.08,207.85)=1.25, p=.289.

7.4.4 The five domains and Global Self-worth: children's self-reported distress and distress behaviour

As mentioned above, Kidcope was completed three times by each child. It was related once to the previously observed blood test and twice to chosen stressors in the common and illness related context. The self-reported distress element forms part of the Kidcope Checklist and was assessed during one-to-one interviews. The children reported three factors on a 5 point Likert-type scale: feeling *anxious/ nervous, sad/unhappy, cross/angry*. The distress score is made up by adding the three factor scores ranging from 1 to 5. The possible range for the distress score is 3 to 15 for each of the contexts. The method (Section 5.1), procedure (Section 5.3.2) and results (Sections 5.10 and 5.11) are reported in Chapter 5.

The children's distress behaviour was assessed during a routine blood test. A structured observational schedule, the OSBD, which includes eight behaviour categories was used. The method (Sections 6.1 and 6.3) procedure (Sections 6.4 and 6.4.1) and results (Section 6.5) relevant here are reported in Chapter 6.

7.4.4.1 Self-reported distress and their competence and Global Self-worth

The distress factors, feeling *anxious/nervous, sad/unhappy,* and *cross/angry,* were compared with the children's perception of competence and self-worth. Although the data was ordinal, it was decided for two reasons to use statistical analyses for

Normally distributed data; first it was in keeping with the existing findings and secondly the data was normally distributed. When Spearman's rho was applied similar results to the ones reported in Table 7.6 were found.

Some weak inverted links between feeling cross and Physical Appearance and feeling cross and Behavioural Conduct within the common and the illness related context were found. The same was true for feeling cross and Global Self-worth in the common context. These results are reported in Table 7.6. No association between feeling cross and self-esteem during the blood test was established.

Table 7.6 Feeling cross or angry and self-esteem

domains	cross or angry COMMON	cross or angry ILLNESS	cross or angry BLOOD TEST
Physical Appearance	r=-.28	r=-.24	r=-.04
	p=.044	p=.081	p=.801
Behaviour Conduct	r=-.27	r=-.25	r= .04
	p=.051	p=.076	p=.758
Global Self-worth	r=-.25	r=-.21	r=-.03
	p=.071	p=.151	p=.861

The better the children felt they were looking the less cross they reported to feel about the stressors in both the common and in the illness related context. The children who perceived themselves to be behaving well, also reported to feel less cross or angry when they talked about an everyday and an illness related stressor. Finally, children who felt generally good about themselves felt less cross when they talked about a stressful situation that had occurred in the everyday context.

A relationship between the way the children felt about their stressors and the way they felt about themselves was sought. Distress scores (where the three factors were added together) for each of the three contexts were compared with the scores reported about children's competence (five domains) and their feeling of global self-worth. Pearson's product-moment was used but no significant results were found. Distress as measured by Kidcope is not associated with children's perception of self-worth as measured by the Self-Perception Profile for Children.

7.4.4.2 Distress behaviour and their competence and Global Self-worth

The results of the distress behaviours observed by the researcher during the blood test and the mean scores of the five domains and Global Self-worth were correlated using Pearson's product-moment. No significant relationships were found between the distress behaviours and the way the children feel about themselves. This result indicates that distress, as measured through observations by the OSBD, is not associated with the children's perception of competence and self-worth as measured by the SPPC.

The results related to the children's perceived competence and feeling of Global-Self worth and coping are summarised at the end of the chapter and reported in Table 7.7.

7.5 Being younger or older: the children's coping and distress

7.5.1 Coping strategies and age

The possible association between *age* and *the number of coping strategies* used to deal with stressors in the common, illness related and blood test contexts was looked at. Scattergrams were examined and Pearson's product-moment correlation was applied comparing the children's age and the number of coping strategies they had used. The possible range for coping strategies is 0 to10 and the age range of the

children was 84 to 194 months. Overall no significant relationships were established between the children's age and the number of coping strategies they reported to have used to deal with their stressors (9 correlations; pairwise with α=.05 level).

In an earlier study by Pretzlik and Hindley (1993), in which 32 school children between the ages of 5 and 10 took part, an age effect was found. Older children tended to use more coping strategies than younger children, both in the common and in the illness related groups. This result confirmed an earlier suggestion by Curry and Russ (1985), Wertlieb *et al.* (1987) and Spirito *et al.* (1991) who found that children around 9 to 11 years old apply a greater variety of coping strategies to deal with stressors than older or younger children. However, no significant age differences were established in Study 1 when 32 school children aged 7 to 10 completed Kidcope.

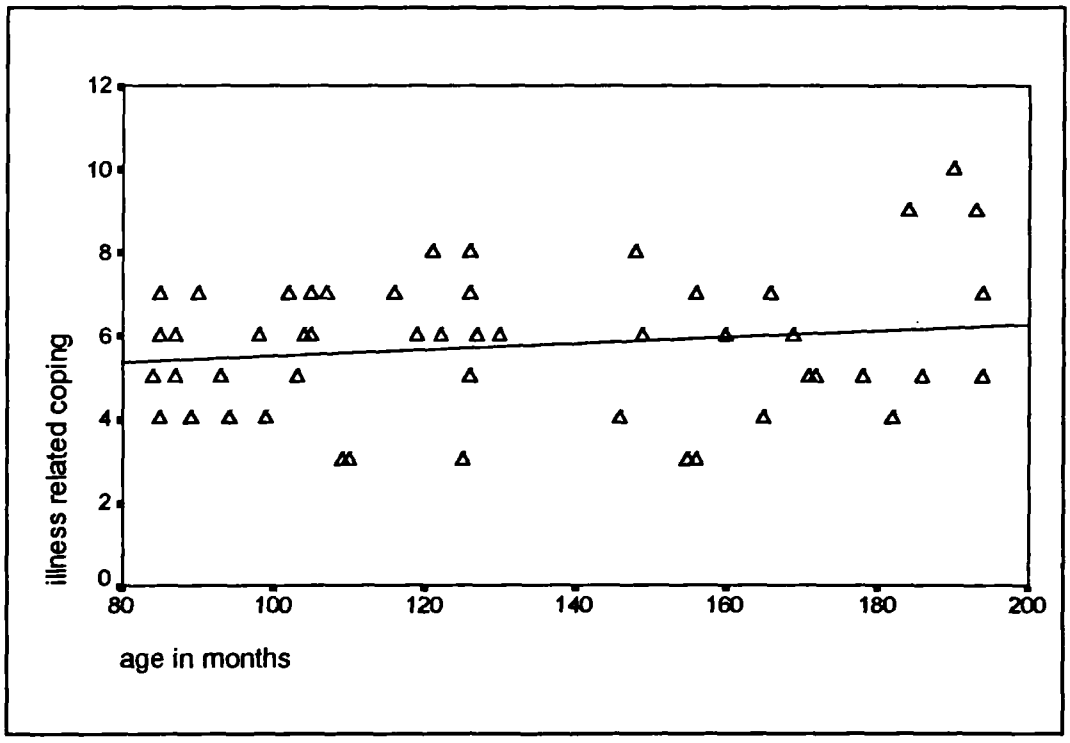


Figure 7.3 An example showing no significant association between the children's age and their coping with a stressor related to the illness (N=53)

An example of 'no significant association between age and their way of coping' (r=.10, p=.219, N=53) is given in Figure 7.3. A summary of the results are recorded at the end of the chapter in Table 7.8.

Having looked at age in months and the total number of coping strategies used and having found that age did not effect this group of children, the sample was split into two groups; *younger* children aged from 84-144 months (n=33) and *older* children aged from 145 to 194 months (n=20). A 2x2 chi-square test was applied to see if the *kinds of coping strategy* used by the children is related to the age group they found themselves in (Table 7.7).

Table 7.7 Associations between younger and older children and the coping strategies they used to cope with a stressors in the three contexts (N=53)

coping	COMMON		ILLNESS		BLOOD TEST	
strategies	χ^2	p value	χ^2	p value	χ^2	p value
Distraction	2.06	. 152	0.61	. 437	9.38	. 002^
Social Withdrawal	0.66	. 416	0.06	. 805	3.52	. 061
Cognitive Restructuring	0.03	. 854	0.17	. 678	3.86	. 049^
Self-criticism	0.11	. 749	0.03	. 871	too few	-
Blaming Others	0.21	. 646	1.47	. 226	too few	-
Problem Solving	1.47	. 226	2.81	. 094	3.61	. 058
Emotion Regulation	0.17	. 678	0.68	. 409	0.11	. 748
Wishful Thinking	3.86	. 049^	0.43	. 511	0.07	. 791
Social Support	0.52	. 469	0.01	. 951	0.24	. 624
Resignation	21.41	<. 001^^	7.16	. 007^^	9.31	. 002^^

^ the younger children used this coping strategy more than the older children

^^ the older children used this coping strategy more than the younger children

Some differences between the two age groups and the kind of coping strategies they used were found in the *blood test* context (Table 7.7). Unlike the other two stressors, the children's blood test stressor was nominated by the researcher. Distraction and Cognitive Restructuring were applied more often by the younger children, whereas older children used Resignation more often indicating a mature understanding that nothing can be done about the blood test.

This result shows a weak age effect in the blood test situation and is consistent with earlier findings, where it was found that younger children showed more distress behaviour (OSBD) during the blood test than older children. The children, who showed more distress behaviour, illustrated by Figure 7.5, also reported having felt more distressed, as measured by Kidcope, than the children who showed less distress behaviour.

However, if coping was affected more by individual characteristics of the child than the situation in which the stressor has occurred, then age effects should be similar across contexts. With the exception of *Resignation*, where the children between 12 and 16 years of age used this coping strategy significantly more when dealing with a stressor in the three contexts than the children between seven and 12, no consistent pattern exists. These age related patterns across contexts, the results of which are presented in Table 7.6, support earlier findings reported in Chapter 5. Here it is suggested that it is not so much the individual differences of the children but the context in which they coped that was a major contributor to their way of coping. The transaction between child, coping and situation should be looked at closely in future studies.

A group of 177 children with a serious illness took part in Spirito *el al.*'s 1995 study. As in the present study, they were asked to recall a stressor in the common and the illness related context. No significant age effects were found across the two contexts. These results by Spirtio *et al.* are similar to the results recorded in Table 7.7 in that few significant differences were found between the children's way of coping and how

old they were. In both studies older children used *Resignation* more often than younger children.

7.5.2 Coping behaviour and age

No significant differences were found between the children's age in months and their coping behaviour (*showing an active interest* or *showing no interest* during the blood test). A *t* test was applied but the result was not significant with $t(52)=0.27$, $p=.786$, indicating that children's active or avoidant coping behaviour was overall not related to how old they are.

7.5.3 Self-reported distress and age

Age in months was correlated with the distress scores recorded with Kidcope using Pearson's product-moment test. The possible range for distress is 3 to 15 and the age range of the children was 84 to 194 months. A weak association between age and distress in the illness related context was found ($r=.24$, $p=.08$, $N=53$) and is illustrated by Figure 7.4. The older the children, the more distress they reported when referring to an illness related stressor.

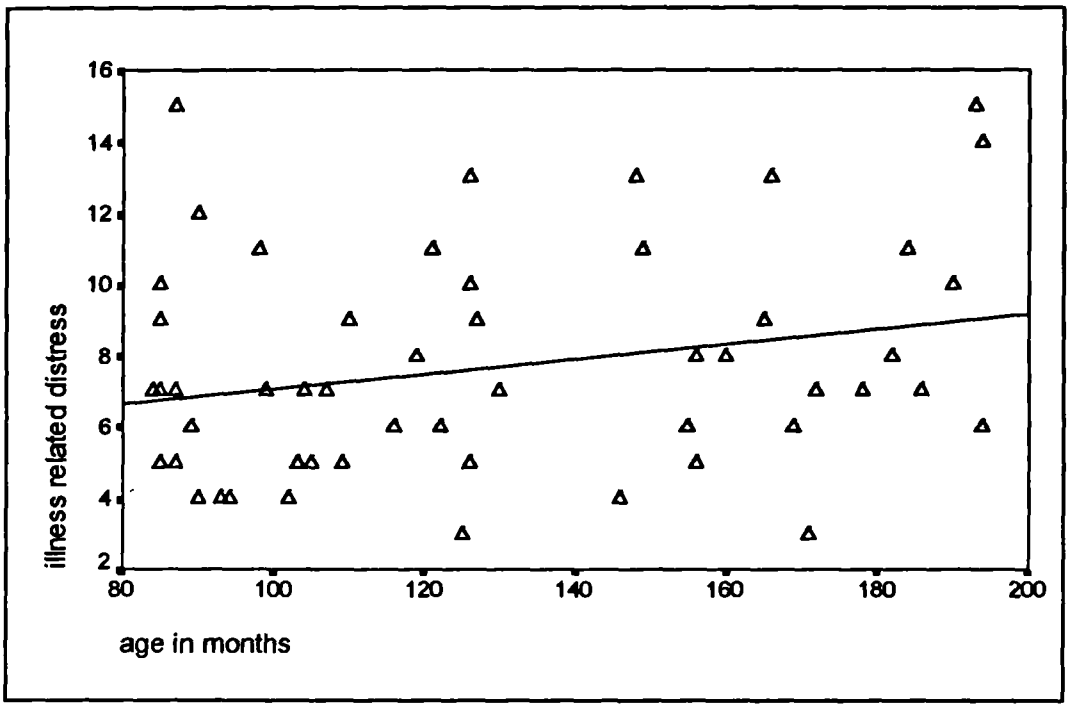


Figure 7.4 An example showing a weak association between the children's age and their self-reported distress when coping with a stressor related to their illness

Age in the common context (r=.09, p=.532, N=53) and in the blood test context (r=-.08; p=.580, N=53) did not effect the intensity of the children's feelings of distress.

7.5.4 Distress behaviour and age

In this study in accordance with other research (for example Jay *et al.*, 1983), an age effect was established between age in months and the children's distress behaviour during the blood test. Pearson's product-moment test was applied and a negative correlation found suggesting that the younger the children, the more distress they displayed (r=-.42, p=.002, N=53). This correlation is represented by a scatterplot (Figure 7.5).

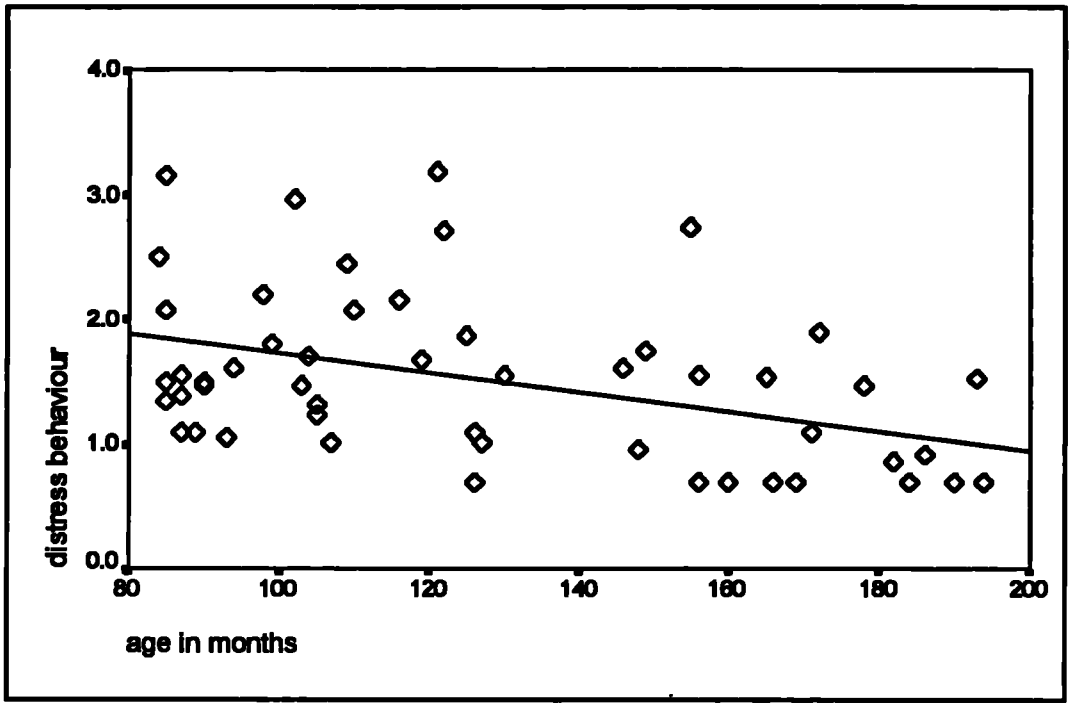


Figure 7.5 Older children displayed less distress behaviour during the blood test than younger children (N=53)

A summary of the results related to the age of the children, their way of coping including self-reported distress and distress behaviour is given at the end of this chapter in Table 7.8.

7.6 Being a girl or a boy: the children's coping and distress

7.6.1 Coping strategies and sex

The Mann-Whitney U test, a statistical test for distribution free data was applied to look for differences between sex and coping. Boys (n=31) and girls (n=22) were found to use a similar number of coping strategies when dealing with stressors in the common, illness related and blood test context (z=1.05, p=.292; z=0.19, p=.847 and z=0.18, p=.861 respectively).

7.6.2 Coping behaviour and sex

Whether the child took an active interest or whether he or she took no interest during the treatment phase of the blood test was systematically observed. A 2x2 chi-square test was applied to see if the sex of the child made a difference to the coping behaviours during the time of the blood test. No significant differences were found between sex and the type of coper they were (31 boys and 22 girls; $\chi^2=0.76$, $p=.384$).

7.6.3 Self-reported distress and sex

The distress element of Kidcope assesses how children feel about a specific stressor. The possible range is 3 to 15. The Mann-Whitney U test for independent samples showed no significant differences between distress and sex in the three contexts (boys n=31, girls n=22; $z=0.01$, $p=.993$ in the everyday-life $z=0.59$, $p=.555$ in the illness related and $z=0.49$, $p=.622$ in the blood test context).

7.6.4 Distress behaviour and sex

The *t* test was applied to investigate boys and girls distress behaviour during the blood test observations. No significant sex effect was found; the children's distress behaviour was similar for both boys and girls; $t(52)=0.32$, $p=.749$.

A summary of the results related to the sex of the children and their coping and distress is recorded in Table 7.8.

7.7 Time since first diagnosis: the children's coping and distress

7.7.1 Coping strategies and experience with the illness

The association between experience, the months since the illness was first diagnosed, and coping was explored using Pearson's product-moment test. The total number of coping strategies reported by the children in the common, illness related and blood test context were examined.

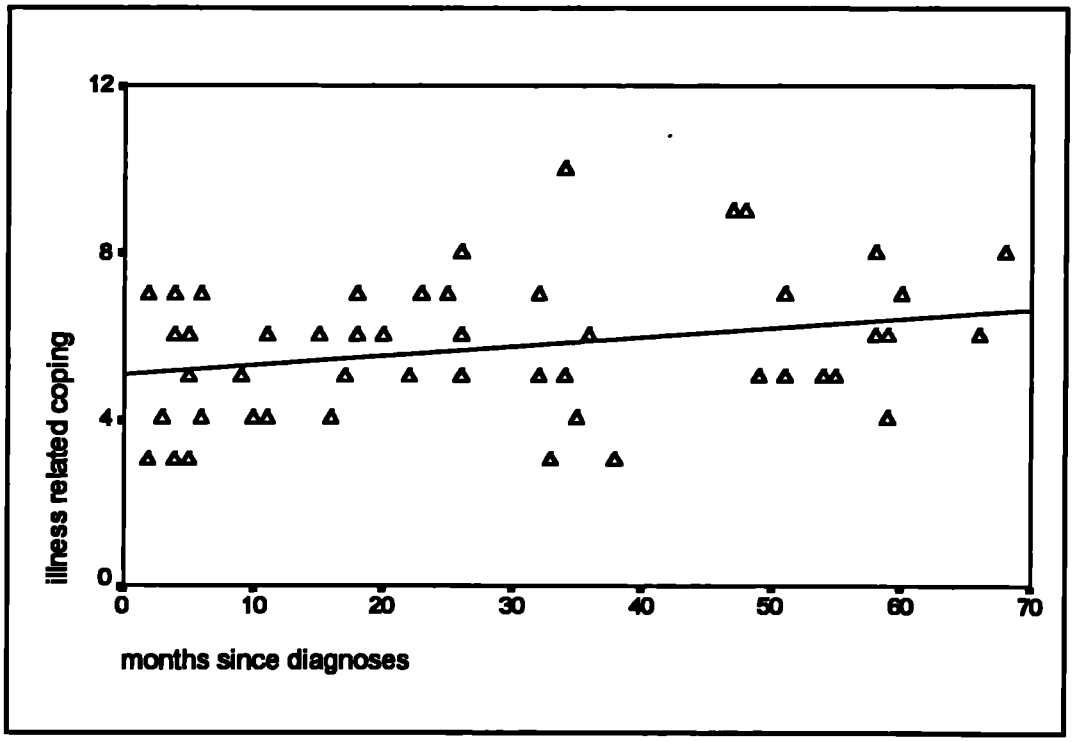


Figure 7.6 The children's experience and the total coping strategies used when coping with a stressor related to their illness (N=53)

In the common and blood test related contexts no significant association between experience and coping strategies was found (r=.22, p=.111 for the common context and r=-.05, p=.725 for the blood test context, both N=53). However, in the illness

related context a weak relationship between experience and the number of coping strategies applied by the children was established (r=.29, p=.034, N=53). The children whose illness had been diagnosed longer ago used more coping strategies when dealing with the illness related stressor than the children who had less experience with the illness. This result is illustrated by Figure 7.6.

Having looked at experience in months and the total number of coping strategies used in each of the three contexts and having found a significant effect between the illness related context and experience, the sample was split into two roughly equal sized groups; children with 2 to 30 months experience (n=29) and children with 31 to 67 months experience (n=24). The objective was to look in more detail at the way children reported having coped.

The 2x2 chi-square test was applied to explore the relationship between the *kind of coping strategy* the children used and the time since the illness was first diagnosed. No associations were established (30 χ^2 tests; pairwise at α=.05 level) between any of the ten coping strategies applied by the children when dealing with stressors across the three contexts irrespective of experience with the illness.

7.7.2 Coping behaviour and experience with the illness

The t test was applied to look for differences between the children's experience with their illness (in months) and the two groups of copers (taking *an active interest* in the blood test or taking *no interest* in the blood test). No significant results were found (t(52)=0.31, p=.756).

7.7.3 Self-reported distress and experience with the illness

When correlating the number of months since diagnoses with the distress scores across the three contexts, it was found that the distress the children had talked about in the illness related and the blood test contexts was not related to their experience

with their illness (r=.20, p=.152 for the illness and r=-.13, p=.343 for the blood test context; in both cases N=53). Nevertheless, a weak link between the children's experience and their reported feelings of distress (possible range 3-15) in the everyday-life situation was established (r=.26, p=.056, N=53); children who felt more distressed when dealing with an everyday stressor had been managing their illness for a greater length of time.

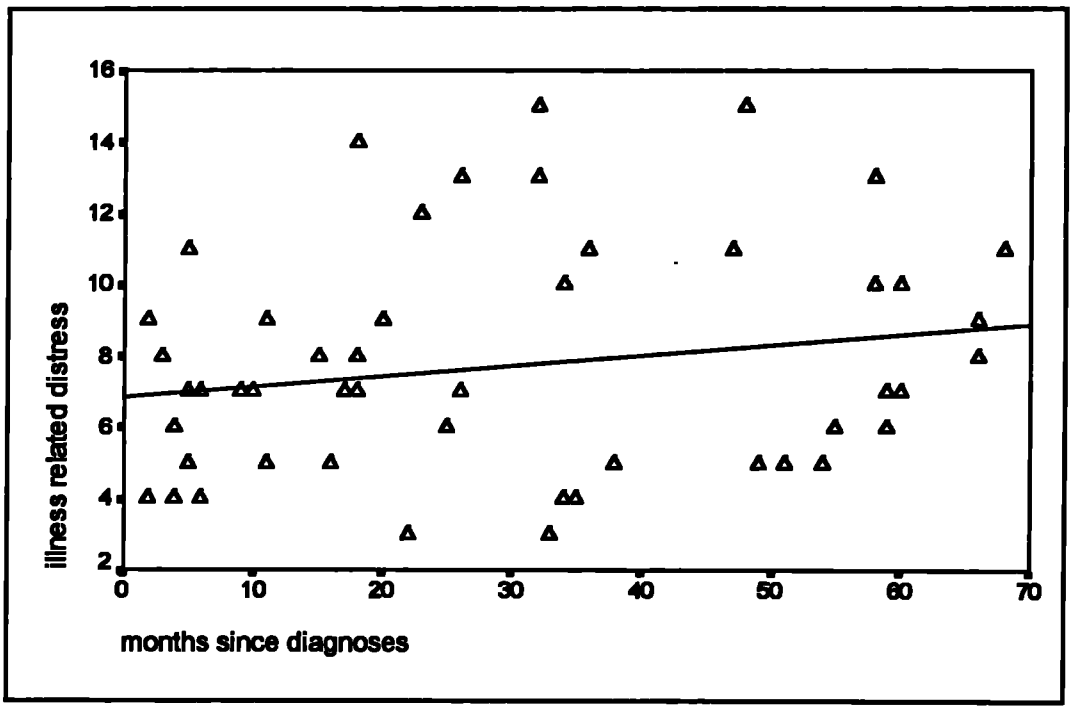


Figure 7.7 An example showing no significant association between the children's experience and their self-reported distress when coping with a stressor related to the illness

Figure 7.7 is an illustration of the random pattern between the time since the children's illness was first diagnosed and their self-reported distress when recalling a stressor in the illness context (r=.20, p=.152, N=53).

7.7.4 Distress behaviour and experience with the illness

The time since the illness was first diagnosed and the children's observed distress during the blood test were compared. No significant association was found in the distress behaviour irrespective of whether the children had been ill for a shorter or a longer period of time (r=-.16, p=.266). Similar results were reported by Jay *et al.* (1983) and Bradford (1990).

Table 7.8 summarises the findings related to experience and coping.

7.8 A summary of the results

In the present study perceived competence and self-worth, age, sex and experience are factors which are defined as *individual differences*. These factors were related to the children's way of coping as measured by the Kidcope Checklist, the OSBD and the two coping behaviours. Few significant results were established between coping and individual differences, suggesting that it is the situation - as discussed in Chapter 5 - and not so much what the child brings to the situation that determines his or her coping. While considering these findings it is of the utmost importance to bear in mind that this group of children is a special group. They all suffered from a serious illness, and it could be that their circumstances overrode the expected developmental effects of coping. Nonetheless having said that the children are special, when asked how they perceived themselves they reported levels of competence and self-worth similar to larger groups of school children in earlier studies.

The children in this research, who took an active interest in the medical procedure, perceived themselves as more competent with school work, physically more attractive and better behaved than the children who showed no interest in the blood test. The active copers' feeling of Global Self-worth was also significantly higher than the children who avoided watching the blood test.

With a few exceptions, the results show that this group of paediatric patients is reasonably homogenous; younger or older children, children with either more or less experience with the illness, and boys and girls have therefore been combined throughout this thesis and unless otherwise stated are treated as one group.

PAGE

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Table 7.8 A summary: individual differences associated with children's coping

	context	self-esteem						age	sex	experience
		School	Social	Athletic	Physical	Behaviour	Self-worth	months	boy/girl	months
	COMMON	r=.08	r=.12	r=-.09	r=.07	r=.07	r=-.05	r=.05	z=1.05	r=.22
		p=.571	p=.400	p=.507	p=.609	p=.612	p=.737	p=.735	p=.292	p=.111
coping	ILLNESS	r=-.09	r=-.16	r=-.02	r=-.05	r=-.14	r=-.07	r=.17	z=0.19	**r=.29**
strategies		p=.541	p=.262	p=.870	p=.714	p=.319	p=.609	p=.219	p=.847	**p=.034**
	BLOOD TEST	r=-.08	r=-.12	r=.01	r=.04	r=-.02	r=-.13	r=-.20	z=0.18	r=-.05
		p=.588	p=.388	p=.981	p=.754	p=.912	p=.370	p=.142	p=.861	p=.725
	COMMON	r=.11	r=.14	r=-.03	r=-.08	r=-.13	r=-.10	r=.09	z=0.01	r=.26
		p=.428	p=.312	p=.841	p=.555	p=.343	p=.496	p=.532	p=.993	p=.056
self-report	ILLNESS	r=.03	r=.04	r=.02	r=-.02	r=-.21	r=-.11	r=.24	z=0.59	r=.20
distress		p=.814	p=.760	p=.861	p=.896	p=.134	p=.451	p=.080	p=.555	p=.152
	BLOOD TEST	r=.03	r=.03	r=-.19	r=-.01	r=-.06	r=-.18	r=-.08	Z=0.49	r=-.13
		p=.847	p=.852	p=.168	p=.949	p=.676	p=.193	p=.580	p=.622	p=.343
coping	BLOOD TEST	t=1.87	t=0.42	t=0.26	t=1.27	t=1.27	**t=3.46**	t=-0.27	χ^2=0.76	t=0.31
behaviour		p=.067	p=.675	p=.796	p=.209	p=.210	**p=.001**	p=.786	p=.384	p=.756
distress	BLOOD TEST	r=.01	r=.07	r=.02	r=.18	r=.05	r=.07	**r= -.42**	t=0.32	r=-.16
behaviour		p=.984	p=.596	p=.859	p=.198	p=.735	p=.618	**p=.002**	p=.749	p=.266

CHAPTER EIGHT
PARENTAL INFLUENCE ON
CHILDREN COPING WITH AN ILLNESS
Study 5

In this study two main components comprise *parental influence*; parental coping and parental presence. In order to investigate to what extent parental and child coping is interdependent the relationship between *parental coping* with their child's illness and the child's own coping processes and coping behaviours are examined and discussed in part I of this chapter. In part II the association between *parental presence* during the blood test and the children's coping processes and their coping behaviours is also considered.

Study 5 part I

First, information about the family structure was recorded, and second, coping patterns used by the parents were assessed in terms of how helpful they perceived them to be when dealing with their child's illness. The parents of the 53 young patients, that is 42 fathers and 42 mothers in two parent families and 11 mothers in one parent families, completed a self-report questionnaire, the Coping Health Inventory for Parents (CHIP).

Details concerning CHIP, its composition and scoring, are described and discussed first, and are followed by the results.

Research questions:

> Is there a relationship between children's coping strategies applied for an illness related stressor and the blood test (Kidcope) and parental coping patterns as measured by CHIP?
>
> Is there a relationship between children's coping behaviour (taking an active interest in the blood test) and parental coping patterns as measured by CHIP?

Is there a relationship between children's self-reported distress for an illness related stressor and the blood test (Kidcope) and parental coping patterns as measured by CHIP?

Is there a relationship between children's distress behaviour (OSBD) during the blood test and parental coping patterns as measured by CHIP?

The measures which assess the core of coping in this study and the method, procedure and results related to them were reported earlier in Chapter 5 (coping and distress *interviews*) and Chapter 6 (coping and distress *observations*). In part I of the present study, the results of the core of coping are explored taking into account parental coping patterns as measured by CHIP.

METHOD

8.1 Parental coping with their child's illness

When dealing with a chronically or seriously ill child, parental coping patterns can be assessed with CHIP; the Coping Health Inventory for Parents (McCubbin *et al.* 1983). The coping inventory measures the extent to which parents find the coping items helpful in dealing with their child's illness. The 45 coping items in turn result in a three factor solution, the coping patterns. The parental *coping patterns*, as measured by CHIP, refer throughout to the adult's way of coping with the illness as a whole and not, as with Kidcope, to a specifically related personal stressor described by the child.

The CHIP inventory looks primarily at what parents do and what they find helpful when faced with their child having a chronic illness. The broad perspective taken by CHIP helps researchers and clinicians form an impression of the way parents cope. Findings are important pointers for health-care professionals seeking to promote

family adjustment to the stresses of longterm illness. Due to the lack of depth and breadth of the instrument, details of which are discussed below, results for research and practise should be interpreted with care.

This coping inventory was first developed by McCubbin, McCubbin and Cauble (1979) as a self-report checklist with 80 items. The items aim to provide information about how parents of children with cystic fibrosis perceived their overall response to the management of family life. Four main areas were used as the basic starting point for developing this measure (McCubbin *et al.* 1983):

> 1) *Network and social support theory*, related to the family's relationship to the community and each other for emotional and social support (Caplan, 1976 and Cobb, 1976 cited in McCubbin *et al.*, 1983).
>
> 2) *Family stress theory*, refers to management of intra- and inter-family dynamics in adjusting to treatment management and general development of the child (Burr, 1976 in McCubbin *et al.*, 1983).
>
> 3) *Individual coping*, involves active and passive psychological adjustments needed to manage anxiety and emotion (Lazarus, 1966 in McCubbin *et al.*, 1983).
>
> 4) *Family medical support*, includes parents' efforts both to communicate with medical staff and other parents, and to manage other practical aspects of the medical care (McCubbin *et al.* 1979).

The coping items, for example 'Doing things with my child', 'Allowing myself to get angry' or 'Talking with the doctor about my concerns for my child', were listed and parents were asked to complete them in terms of how *helpful* (0-3) they were/are to them in managing the home-illness situation. The development of CHIP (McCubbin *et al.*, 1979) was influenced by a hierarchical approach to the organisation of what they called coping behaviours. Using this approach two levels were defined: *coping behaviours* (the 80 coping items) and *coping patterns* (a combination of coping behaviours into specific subscales).

The 185 parents, mothers and fathers, of children with cystic fibrosis, who took part in the original study, rated 30 of the 80 items as 'not applicable' to them. These 30 items as well as five other items, which showed minimal variance, were left out in the revised version of the Coping Health Inventory for Parents with 45 items (McCubbin *et al.*, 1983).

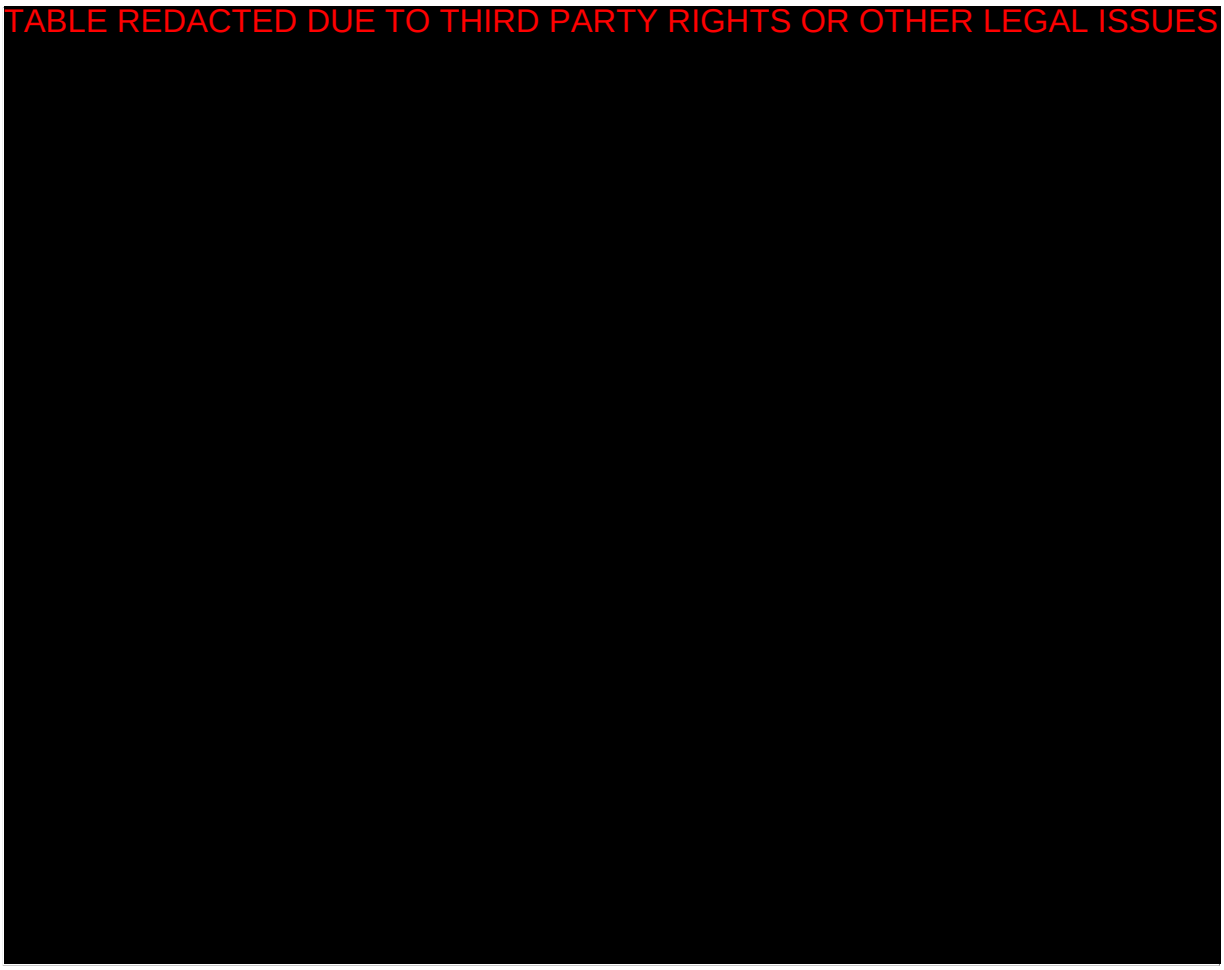
There were 100 families, 90 two parent and 10 single parent, with one or more children with cystic fibrose who took part in the study (McCubbin *et al.*, 1983) where the validity and reliability of CHIP were tested. Two main measures were used: the Family Environment Scale (Moos, 1974 cited in McCubbin *et al.*, 1983) and the indices of the child's health as defined by the Medical Director (the Height/Weight Index and the Pulmonary Functioning Index). Details are reported in Section 8.1.1.

Factor analysis concluded that the results from the completed questionnaires fell into three clear coping patterns: Coping Pattern I is made up of 19 items and relates to family life and relationships as well as to the parents outlook on life. Coping Pattern II is made up of 18 items. These items relate to the parents' perception of the efforts they made to maintain a sense of their own well-being through social relationships. Coping Pattern III consists of eight items, which focus on the impact of the child with cystic fibrosis on parents and the medical staff and on programs of contact with other parents of children with the same illness.

Given the diverse practical and emotional demands associated with different chronic diseases, there is every reason to suppose that parents may find certain coping patterns more helpful than others when dealing with some diseases. Using CHIP (McCubbin *et al.* 1983) as the basis of their study, Eiser and Havermans (1992) looked at mothers and fathers' ways of coping with chronic childhood disease. Their UK sample included a total of 169 families where the children suffered from one of five conditions: diabetes (n=94), asthma (n=29), epilepsy (n=23), cardiac conditions (n=12) and leukaemia (n=11).

From the original 45 items only 33 were selected for use. For an example of the questionnaire see the appendix. Those 33 were chosen for two main reasons: high loading on the three original factors mentioned above and the appropriateness of the wording and content of the items to a British sample. The original 4 point scale was extended to a 5 point scale from 1 *not at all helpful* to 5 *very helpful indeed.*

Table 8.1 The Coping Health Inventory for Parents: the four coping patterns (Eiser and Havermans, 1992)



When Eiser and Havermans (1992) applied principal components factor analysis to data of the completed inventories from 169 fathers and 169 mothers, four factors

emerged. Results were similar for fathers and for mothers. These coping factors were identified as *Autonomy* (looking after oneself), *Medical Care* (trusting medical staff), *Information/Social Support* (learning from others in a similar position) and *Family Support* (keeping the rest of the family together). Examples are provided in Table 8.1 and in Appendix VII.

The main difference between the McCubbin *et al.* (1983) and the Eiser and Havermans (1992) studies is that one had been developed with a specific patient sample in the United States (45 coping items), whereas the other was anglicised (33 coping items selected from the 45 original items) and used with a diverse patient group. In the American study three coping patterns were identified, whereas in the latter study four emerged. Also, the Likert-type scale was amended from the original 0-3 scale to a 1-5 scale.

It was decided that CHIP (McCubbin *et al.*, 1983) was the appropriate measure to use in the present study as CHIP had been adjusted to a British sample and used with parents of children other than with cystic fibroses by Eiser & Havermans (1992).

8.1.1 Validity and reliability of CHIP

The three coping patterns were first validated by McCubbin *et al.*, and reported in their 1983 paper. Coping pattern I (maintaining family integration), coping pattern II (strengthening the self) and coping pattern III (gaining an understanding of the medical situation) represented 71% of the variance of the original correlation matrix. Cronbach's alpha was applied to the items for each coping pattern, and indicated reliabilities of .79, .79 and .71 respectively. The factors show reasonable stability. Test-retest data was not reported. The CHIP inventory sets out to measure an association between parent's way of coping and their child's illness. Therefore, as is reported below, the answers given by parents relate to the family circumstances and the child's state of health at the time of the interview. These circumstances may fluctuate over time.

The main aim of the McCubbin *et al.* (1983) study was to investigate the three coping patterns and their relationship with six subscales associated to the family's environment as well as the two indices related to the child's state of health. That is to say, validation took place against established criteria of changes in the children's health and family-life. Changes in the child's health were assessed in two ways: the Height and Weight Index and the Pulmonary Functioning Index. Six of the ten subscales, Cohesion, Expressiveness, Conflict, Personal Growth, Organisation and Control, from the Family Environment Scale (Moos, 1974 in McCubbin *et al.*, 1983) were used and compared with the three coping patterns as measured by CHIP. The three parental coping scores were correlated with these measures.

Mothers' three coping patterns were validated by their association with family cohesiveness (r=.21, p<.01 and r=.19, p<.05, n=100) and expressiveness (r=.19, p<.05, n=100). The associations, although statistically significant, are weak and explain no more than 4% of the variance for each of the components. Two of the fathers coping patterns were validated by their association with family cohesiveness (r=.36, p<.01, n=90), conflict (r= -.21, p<.05, n=90), organisation (r=.32, p<.01, n=90) and control (r=.19, p<.05, n=90). Again, as with the result of the mothers, exploratory values are weak. Variance of between only 4% and 10% is explained, leaving a large proportion of the variability between parental coping and the family environment unaccounted for.

Parental coping patterns were found to compare with the children's health measures. The mothers' efforts to maintain family integration, cooperation and an optimistic definition of the situation are said to play a significant part in positive gains in the child's Height/Weight Index (r=.20, p<.05, n=100). The fathers' efforts to maintain social support, self-esteem and psychological stability are said to be related to the improvements of the cystic fibrosis children's health as reflected in both the Height/Weight Index (r=.22, p<.05, n=90) and the Pulmonary Functioning Index (r=.31, p<.01, n=90). Overall some weak associations, explaining 4% to 9% of the variance between parental coping and the criterion indices or changes in the children's

health, were established. It is assumed that parental coping influences the child's health. This may be so, on the other hand it may well be that parents perceive coping patterns to be more helpful when their child is doing better.

8.2 The Coping Health Inventory for Parents: the procedure

In this study a total of 95 parents, a response rate of 100%, completed the CHIP inventory (42 two parent families and 11 single parent families headed by mothers). The researcher sat with the parent helping with queries if and when they occurred. Parents from two parent families answered the questions on two separate occasions in the hospital. In a few cases it was necessary to give the second questionnaire and a self-addressed, stamped envelope to be completed at home.

8.2.1 The subscale structure

The 33 items were analysed according to Eiser and Havermans' instructions and in terms of the four parental coping patterns: *Autonomy*, 12 items; *Medical Care*, 7 items; *Information/Social Support*, 5 items and *Family Support*, 9 items (Appendix VII).

8.2.2 The question format

The CHIP inventory, a paper and pencil test, was completed by choosing the answers to each of the 33 items on a simple 5 point Likert-type scale from 1 *not at all helpful* to 5 *very helpful indeed.*

RESULTS

So far the children's coping and distress (Chapters 5 and 6) as well as the association between coping, distress and individual differences (Chapter 7) have been explored. In this chapter the focus shifts from the child to the child and his or her parents.

The parents coping is described and relationships between the different parent groups, the coping subscales and the children's way of coping and distress are sought. Results of the four coping subscales are reported for the three parent groups in Section 8.3.1, associations between the children and the parents' coping in Section 8.3.1.1 and between the children's distress and their parents coping in Section 8.3.1.2.

8.3 The Coping Health Inventory for Parents: parental coping and children's coping and distress

The 33 statements of the CHIP are broadly based and relate to the way parents cope with their child's illness. They are answered on a 1 to 5 Likert-type scale and make up four subscales/coping patterns. The mean scores of the subscales were used when the data were analysed (Table 8.2).

The scale produces ordinal data. Here, as in previous work reported by Eiser and Havermans (1992), analysis for Normally distributed data were used when possible; inspection of the distribution of the mean scores did show the data to be Normally distributed. However distribution-free tests were used where the group size was small ($n<10$).

8.3.1 The four coping patterns: similarities and differences between parent groups

This inventory is made up of four coping subscales and the parents are grouped as fathers and mothers of two parent families and mothers of single parent families. All the single parent families were headed by mothers.

The parents' perception of the way they cope with their child's illness is illustrated by Figure 8.1 and mean scores and standard deviations are presented in Table 8.2. The mean scores of how helpful (from *not at all helpful* 1 to *very helpful indeed* 5) the parents found the coping items to be, for example, 'Becoming more self-reliant and independent', 'Reading about how other people in my situation handle things' or 'Talking to the doctor about my concerns about my child' form the basis of these analyses (Table 8.1).

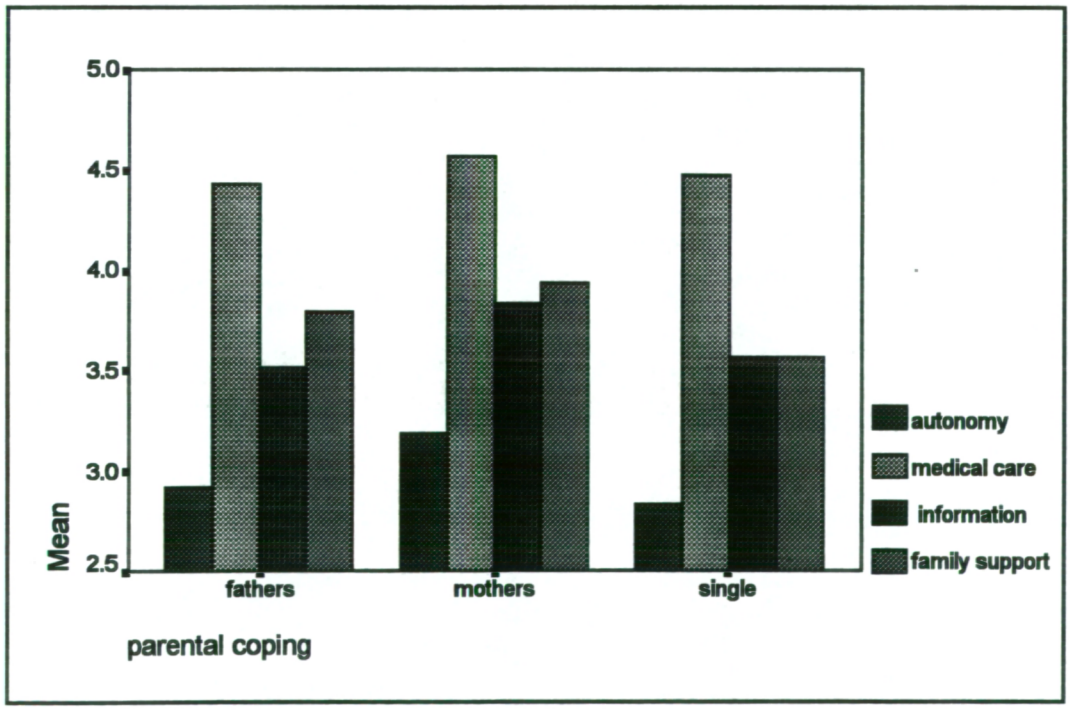


Figure 8.1 The Coping Health Inventory for Parents: the four coping patterns and the three parent groups (n=42, n=42 and n=11)

Medical Care was reported by all three parent groups to be the most helpful coping pattern when dealing with their child who had either leukaemia or aplastic anaemia. *Family Support* was rated to be more helpful than *Information/Social Support* and *Autonomy* was found to be less helpful than the other three coping patterns.

Table 8.2 Describing the four coping patterns (N=95)

	subscales	fathers n=42		mothers n=42		single mothers n=11	
rank		mean	*SD*	mean	*SD*	mean	*SD*
1	Medical Care	4.43	0.44	4.57	0.39	4.48	0.39
2	Family Support	3.79	0.67	3.94	0.61	3.57	0.63
3	Information	3.52	0.89	3.84	0.76	3.57	0.78
4	Autonomy	2.92	0.81	3.19	0.83	2.83	0.77

Eiser and Havermans (1992) in their study asked 169 families of children with a chronic illness to complete the adjusted CHIP inventory. Eleven families had a child with leukaemia and the parental coping mean scores, although comparatively lower than the mean scores reported Table 8.2, are similarly ranked: (1) *Medical Care,* 4.29; (2) *Information/Social Support,* 3.55; (3) *Family Support,* 3.19 and (4) *Autonomy*, 2.44.

To compare the different parent groups and their way of coping two types of analyses were used. First, a *within-subject* design for fathers and mothers was applied. The within analysis is powerful as it is able to control parts of the children's individual differences and aspects of the family setting. Second, a comparison involving parents and single parents had to be done as a *between-subject* factor. It produced a less convincing result.

A MANOVA was conducted to compare mean scores of the CHIP subscales (within-subjects) with fathers and mothers coping patterns (within-subjects). The variable *coping* is made up of four factors (Autonomy, Medical Care, Information/Social Support and Family Support) and the variable *parents* of two factors (mothers and fathers coping). The Mauchly sphericity test was non-significant, and adjustment to the degree of freedom was therefore not necessary.

The within-subject effect of the four coping patterns was significant $F(3,123)=87.62$, $p<.001$, confirming results reported in Table 8.2. The within-subject effect for the two groups was also significant $F(1,41)=7.25$, $p=.01$ implying overall differences between the fathers and mothers coping patterns. Mothers reported that the coping items were helpful to them; more helpful than to the fathers. No overall interaction between fathers, mothers and coping was established $F(3,123)=0.80$, $p=.495$. This finding is clearly illustrated by Figure 8.1.

Single mothers (n=11) and their coping patterns were compared with fathers (n=42) and with mothers' (n=42) way of coping with their children's illness. In both cases a MANOVA was used to look at the mean scores for the four CHIP subscales (within-subjects) and the two parent groups (between-subjects). The between effects for single mothers and fathers $F(1,51)=0.32$, $p=.571$ and single mothers and mothers $F(1,51)=1.86$, $p=.179$ were non-significant, indicating no overall differences between parental coping patterns. These non-significant results do not seem to reflect the mean differences as illustrated by Figure 8.1. This may be due to the two reasons that there are only 11 people in one of the groups and that the between-subject design of the multivariate analysis of variance is less powerful than the within-subject design.

Differences between the four coping subscales were established confirming the findings reported in Table 8.2. For the fathers and the single mothers the within-subject effect was $F(3,153)=53.69$, $p<.001$ and for the mothers and the single mothers (the Mauchly sphericity test was significant where $p=.033$ and the Greenhouse-Geisser Epsilon was applied) the within-subject effect was

$F(2.62,133.58)=51.17, p<.001$. No overall interaction involving coping patterns and the parent groups was established; for the fathers, the single mothers and coping the results were $F(3,153)=0.53$, $p=.664$, and for the mothers, the single mothers and coping the results were $F(2.62,133.58)=0.70$, $p=.536$. These findings are represented by Figure 8.1.

Table 8.3 Correlation coefficients: intercorrelations between parental coping and single mothers (n=11)

coping patterns	1	2	3	4
1 Autonomy	-			
	-			
2 Medical Care	$r=.58$	-		
	$p=.055$	-		
3 Information/ Social Support	$r=.69$	$r=.50$	-	
	$p=.018$	$p=.126$	-	
4 Family Support	$r=.46$	$r=.60$	$r=.32$	-
	$p=.159$	$p=.051$	$p=.343$	-

The correlation coefficients from the four coping subscales for the single mothers are reported in Table 8.3. They are relatively high ranging from $r=.32$ to $r=.69$ explaining between 10.2% and 47.7% of the variance. All are positive, and *Autonomy* and *Information/Social Support* are significantly related to each other, showing some consistency between the subscales. Being a small group, the significance of the results cannot be compared with the results of the fathers and the mothers from the two parent families which are reported in Table 8.4.

Table 8.4 Correlation coefficients: intercorrelations between parental coping and mothers (n=42) and fathers (n=42)

	coping patterns	Mothers 1	2	3	4	Fathers 1	2	3	4
Mother	1 Autonomy	-							
		-							
	2 Medical Care	r=.19	-						
		p=.234	-						
	3 Information/	r=.42	r=.50	-					
	Social	p=.006	p=.001	-					
	Support								
	4 Family	r=.57	r=.49	r=.51	-				
	Support	p<.001	p=.001	p=.001	-				
Father	1 Autonomy	r=.50	r=.18	r=.20	r=.39	-			
		p=.001	p=.242	p=.208	p=.011	-			
	2 Medical Care	r=.13	r=.22	r=.14	r=.16	r=.50	-		
		p=.409	p=.156	p=.368	p=.309	p=.001	-		
	3 Information/	r=.46	r=.19	r=.31	r=.39	r=.47	r=.57	-	
	SocialSupport	p=.002	p=.229	p=.044	p=.011	p=.002	p<.001	-	
	4 Family	r=.27	r=.15	r=.23	r=.41	r=.50	r=.52	r=.46	-
	Support	p=.079	p=.338	p=.150	p=.066	p=.001	p<.001	p=.002	-

As with the single mothers (Table 8.3), all correlation coefficients for fathers and mothers were positive (Table 8.4). The correlation coefficients from the mothers are statistically significant in five out of six cases for the mothers and in all six cases for the fathers. These results indicate reasonable consistency between the four subscales accounting for up to 33% of the variance.

There was significant agreement between fathers and mothers' perceived helpfulness of *Autonomy* (r=.50, p=.001, n=42) and *Information/Social Support* (r=.31, p=.044,

n=42). The mothers reported *Medical Care* and *Family Support* to be overall more helpful than the fathers (Figure 8.1).

8.3.2 Parental coping: children's self-reported coping and their coping behaviour

Although the mothers and the single mothers and the fathers and the single mothers were not found to significantly differ in their way of coping (Section 8.5.1) it was decided to keep the parent groups separate. It was not possible to define the single mothers reliably or to determine which of the other two parent groups they would fit with; was it with the same sex parent or was it the assumed main wage earner of the family?

The Kidcope Checklist was administered through one-to-one interviews and completed three times by each of the children. Children's way of coping is related to specific stressors chosen by them and partly assessed through coping strategies and whether or not they used them. The method (Sections 4.1 and 4.2), procedure (Section 5.3) and results (Sections 5.4, 5.5. and 5.6) relevant to this chapter have been reported in Chapter 5.

Parental coping patterns and the children's coping behaviour during the blood test as well as their way of coping with the illness and the blood test were explored. The children's interest in the blood test had been assessed through systematic observation and is defined as 'taking an active interest', a measure devised for this study. The coping behaviour was recorded for its presence or absence during four continuous 15 second intervals in the treatment phase of the blood test, giving a possible range of 0 to 4 for each observation. As the data was not Normally distributed, but represented by a U-type shaped curve, the children were put into one of two groups. The two groups of copers are defined as *actively interested* (n=23) and *not interested* (n=30). The method (Sections 6.2 and 6.3), procedure (Section 6.4.2) and results (Section 6.7) relevant to this part of the study were reported in Chapter 6.

Although it did not form part of the research question, preliminary analyses found no significant differences between results from CHIP and the children's sex, age and time since the illness was first diagnosed. The 53 children are treated as one group throughout this part of the result section.

8.3.2.1 The level of significance

In the next few sections the results of several statistical tests will be discussed. Where multiple comparisons are made Bonferroni's inequality will be used to adjust the level of significance in order to control for Type I error. However, this generally increases the probability of Type II errors so significant pairwise comparisons at the conventional at α=.05 will also be reported. Given the increased likelihood of Type I error these results should be viewed with caution.

8.3.2.2 Parental coping and children's coping strategies

To explore whether or not mothers and fathers' coping patterns are related to their child's way of coping, the association between children's coping, the total number of coping strategies they reported to have used in the illness related and the blood test context, and parental coping patterns is considered. The Pearson's moment product correlation test was applied. One significant result was found.

The children, whose mothers found *Information/Social Support* more helpful, reported having used more coping strategies in the blood test context (r=.31, p=.05, n=42) than children, whose mothers perceived this coping subscale to be less helpful. This result, although significant, has to be interpreted with caution due to the number of tests that had been applied (24 correlations; pairwise at α=.05 level).

Next, the children's *individual coping strategies* were compared with the parents coping patterns as measured by CHIP. Due to the small sample size the Mann-Whitney U test was used for *single mothers* and their coping patterns.

Mothers who felt that good *Medical Care* helped them cope with their child's illness had children, who reported to have used *Cognitive Restructuring* 'I tried to see the good side of things' when referring to a stressor related to their illness (z=2.158, p=.029, n=3, n=8). Children from single parent families, who reported resorting to *Blame Others* when recalling an illness related stressor, had mothers, who found *Autonomy* a helpful coping pattern (z=2.457, p=.014, n=7, n=4) and children who had used *Distraction* during the blood test had mothers who found *Information/ Social Support* a helpful coping pattern (z=2.032, p=.042, n=5, n=6). These three significant results may be due to chance as a large number of tests had been applied (four coping subscales, two contexts, one parent group and ten coping strategies; 80 Mann-Whitney U tests pairwise at α=.05 level).

The t-test was applied to look for differences between the *individual coping strategies* and *fathers and mothers'* coping patterns (four coping subscales, two contexts, two parent groups and ten individual coping strategies; a total of 160 t-tests were applied; pairwise at α=.05 level). Only five significant results were found and are reported below. In terms of the probability level used these could be due to chance.

Social Support, one of the children's coping strategies used to deal with their *illness related* stressor, was significantly related to three out of four coping patterns used by the mothers when coping with their child's illness.

The mean scores of the maternal coping patterns are illustrated by Figure 8.2. Children from two parent families who used *Social Support,* 'I tried to feel better by spending time with others like family, grown-ups or friends' to help them cope with a stressor in the illness related context had mothers, who found *Medical Care* (t(40)=3.62, p=.001), *Information/Social Support* (t(40)=3.51, p=.001) and *Family Support* (t(40)=2.80, p=.008) more helpful when coping with their child's illness than other parents. No significant difference was detected for *Autonomy* in the two groups (t(40)=0.36, p=.717).

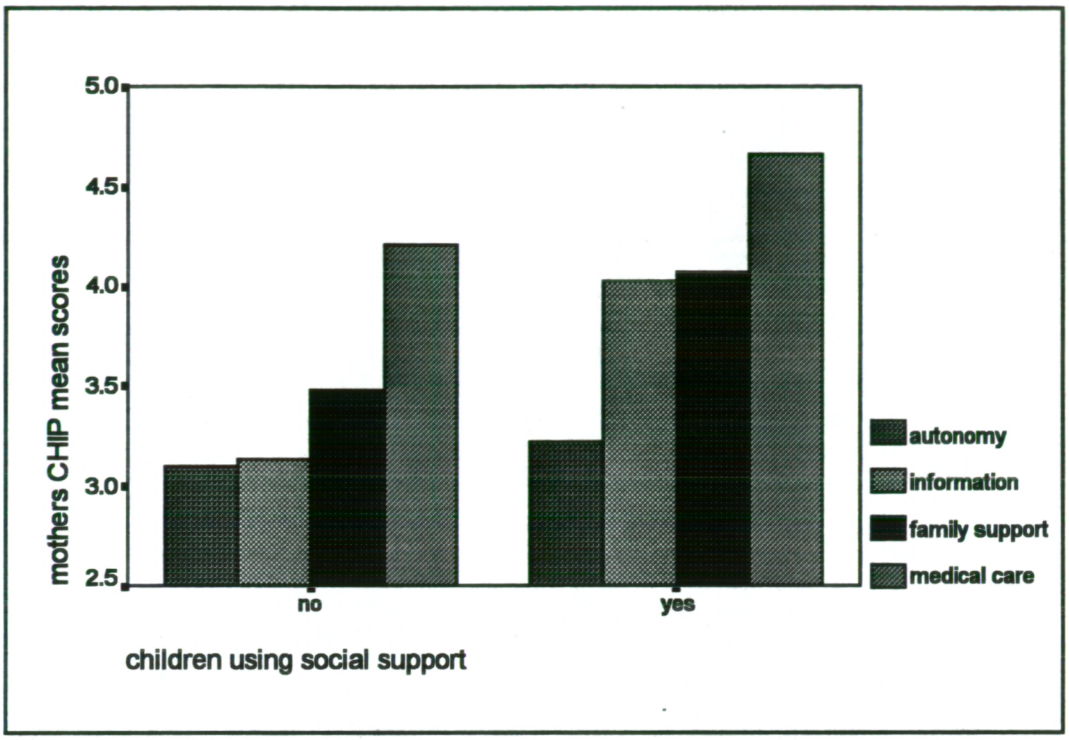


Figure 8.2 The children using Social Support when coping with a stressor related to the illness and mothers coping patterns related to their child's illness

Forty children reported having used Social Support when dealing with a personal stressor related to their illness. Thirteen children did not use this coping strategy and generally their mothers reported coping patterns as less helpful than the mothers whose children had used Social Support. As three out of the four maternal coping subscales are associated with the children's coping strategy Social Support, it can be said, with caution, that this result should be looked at more closely with a larger group of families in future studies.

A MANOVA was applied to compare the mean scores between mothers coping patterns and their children's use of the coping strategy Social Support. The within-subject variable *coping* was made up of four factors, Autonomy, Medical Care, Information/Social Support and Family Support (Table 8.2) and the between-subject

variable *Social Support* was made up of two factors (whether or not this coping strategy was used to deal with an illness related stressor selected by the child).

The between-subject effect was significant F(1,40)=8.95, p=.005 implying overall differences between children who used Social Support when dealing with an illness stressor and the children who did not. The test of Mauchley's sphericity was significant (p=.016), and therefore the Greenhouse-Geisser Epsilon was used to adjust the degree of freedom. A significant interaction between mothers' coping patterns and the children's use of Social Support was established F(2.50, 99.84)=2.91, p=.048.

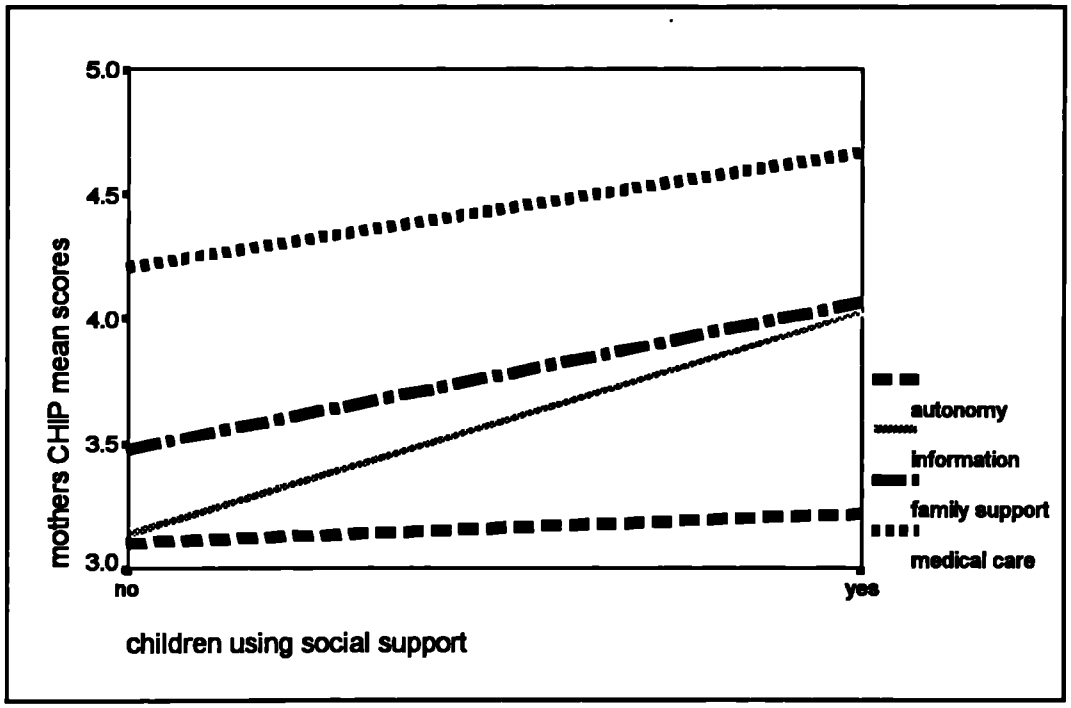


Figure 8.3 Interaction between Social Support and mothers coping patterns

Figure 8.3 shows Autonomy, Medical Care and Family Support to be more or less parallel. It appears that the mother's coping pattern *Information/Social Support* is

the decisive variable bringing about the interaction between the parents' coping patterns and the children's application of the coping strategy *Social Support* to their illness related stressor.

When children did not use *Blaming Others* in relation to the blood test their mothers reported *Family Support* to be helpful (t=(40)=3.13, p=.003). When the children did not use *Resignation* during the blood test their fathers reported Family Support to be helpful (t(40)=2.04, p=.048). These are just a few significant results and should be interpreted with caution due to the large number of tests, which had been applied to look for an association between children's way of coping with a specific stressor and their parents coping patterns when coping with their child's illness in general.

8.3.2.3 Parental coping and children's coping behaviour

The children's coping behaviour, where they showed either *active interest* or *no interest* in the blood test, was compared with their parents' general coping patterns. The t-test was applied for the mothers (n=42) and the fathers (n=42), and to compensate for the small sample size the Mann-Whitney U test was used for the group of 11 single mothers.

No significant differences were found between parental coping and the children's coping behaviour (16 t-tests and four Mann-Whitney U tests were applied; pairwise at α= .05 level). It can therefore be said that parental coping with their child's illness as measured by CHIP has no influence that could be detected above chance on the children's coping behaviour.

8.3.3 Parental coping: children's self-reported distress and their distress behaviour

The OSBD was used to assess, through observation, children's distress behaviour while their blood was taken during a routine blood test. The method (Sections 6.1

and 6.3) procedure (Sections 6.4 and 6.4.1) and results (Section 6.5) relevant to Chapter 8 have been reported in Chapter 6.

The self-reported distress element forms part of the Kidcope Checklist and was completed by the children during one-to-one interviews. Feeling distressed was related to the specific stressor and was assessed through three factors on a 5 point Likert-type scale, *anxious/nervous, sad/unhappy and cross/angry*. The distress score is made up by adding the three factor scores with a possible total score ranging from 3-15. The method (Section 5.1), procedure (Section 5.3.2) and results (Sections 5.10 and 5.11) from the distress element of Kidcope relevant to this part of Chapter 8 were reported earlier in Chapter 5.

8.3.3.1 Parental coping and children's self-reported distress

The results of parental coping patterns for the three parent groups and the four subscales were compared, using Pearson's product-moment correlation test, with the children's self-reported distress in the illness related and the blood test contexts (three parent groups, four subscales, distress in two contexts; 24 correlations; pairwise at $\alpha = .05$ level). No significant relationships were found between children's self-reported distress and their fathers' coping. However, an association was established between mothers coping and their children's feeling of distress.

Two negative correlations were found between the children's feeling of distress and their mothers' coping patterns. Firstly, children, who reported feeling *less distressed* during the blood test, had mothers, who found *Family Support* a helpful coping pattern ($r = -.31$, $p = .049$, n=42), and secondly children from single parent families, who reported feeling *less distressed* in the illness related context, had mothers who found *Family Support* helped them cope better with their child's illness ($r = -.65$, $p = .032$, n=11).

8.3.3.2 Parental coping and children's distress behaviour

Children's distress behaviour observed during the blood test and the four parental coping subscales were compared using Pearson's product-moment correlation test (three parent groups, four subscales and distress behaviour). No significant results were found (12 correlations; pairwise at α=.05 level) and results ranged from r=.35, p=.293, n=11 to r=-.05, p=.763, n=42. Parental coping as measured by CHIP does not appear to influence the way children behave as measured by the OSBD during the blood test.

8.4 A summary of the results so far

In the present study, parents' perception of their own coping and children's coping as reported by *the children themselves* and assessed through *an independent observer* were combined for the first time.

A large number of analyses were undertaken to look for associations between parental and child coping; they yielded few significant results. The four coping patterns were overall found to be more helpful by the mothers from two parent families than by the fathers and the single mothers. The mothers from two parent families, whose children used Social Support to help them cope with the self-selected illness related stressor, reported the coping patterns considered here as more helpful than the mothers of children who did not. Social Support is a coping strategy whose contribution to positive outcome is discussed in adult literature as well as in literature related to families of children with an illness or physical handicap (e.g. Aldwin, 1994; Eiser, 1990, 1993). The findings which relate to the children's dependence on Social Support require further investigation in future studies.

The measures used, both self-report and observation, to assess the children's way of coping are complex and looked at *specific aspects* of coping. The instrument

employed, however, to assess parental coping is limited in sofar that it assessed no more than four factors related to the child's illness in *general terms.* The lack of concrete results in this part of Study 5 may be due to the differences in what the instruments measured and how they measured it.

Study 5 part II

Whether a parent's presence or absence during the blood test influences the children's way of coping will be considered in part II of this chapter.

Research questions included:

> Is there a relationship between children's coping strategies applied during the blood test (Kidcope) and parental presence?
>
> Is there a relationship between children's coping behaviour (taking an active interest in the blood test) and parental presence during the blood test?
>
> Is there a relationship between children's self-reported distress during the blood test (Kidcope) and parental presence?
>
> Is there a relationship between children's distress behaviour (OSBD) and parental presence during the blood test?

Details of the core of coping and the measures which can assess it were first reported in Chapter 5 (coping and distress *interviews*) and Chapter 6 (coping and distress *observations*). Here, results of the core of coping are looked at taking into account parental presence or absence during the blood test.

METHOD

8.5 Parental presence or absence during the blood test

Each child was observed during a routine blood test within the hospital setting and at the same time the presence or absence of a parent was recorded. The recording took place as a simple *yes* for parental presence during the blood test and a *no* for parental absence. These observations were carried out in conjunction with the observations of the children's distress behaviours as measured by the OSBD checklist. The self-reported coping and distress data, as measured by Kidcope, refer back to the same period.

8.6 Parental presence: the procedure

All data were gathered in two London hospitals by the same researcher. Due to the gravity of the illness children were accompanied for most of the time by either the father, the mother or in a few instances a grand-parent or gardian. The choice of whether or not a family member was present during a medical procedure, such as the blood test, was left up to them and/or the child.

RESULTS

Parental presence or absence during a routine blood test is examined and related to the children's way of coping. Parental presence and the number and kinds of coping strategies children reported to have used during the blood test, and parental presence and children's coping behaviour during the blood test will be presented in Section 8.7.1. Parental presence and children's self-reported distress related to the blood test and their distress behaviour during the blood test are reported in Section 8.7.2.

8.7 Parental presence during the blood test and the children's coping and distress

The decision whether or not a parent was with the child during the blood test was up to the individual child or/and parent. *Parental presence* (n=29) or *absence* (n=24) was recorded as a simple *yes* or *no*. Similarities and differences between the two groups were looked at.

As a preliminary analysis a 2x2 chi-square test was applied to look at parent groups and their presence during the blood test. No differences were established between the two parental groups; parents from two parent families and single parents being present or absent during the blood test, $\chi^2=0.72$, p=.518.

8.7.1 Parental presence: children's self-reported coping and their coping behaviour

Data on the children's way of coping were recorded during one-to-one interviews. The Kidcope Checklist was completed three times by each child; once relating to a specific medical procedure, i.e. the blood test which had been observed earlier, and twice to the child's chosen stressors (one in the everyday context and the other in the illness related context): coping strategies reported to have been applied by each child for each stressor were recorded and analysed.

In this part of the study results from the Kidcope Checklist, the *coping strategies* the children reported to have used during the *blood test,* are compared with the parental presence or absence during the same procedure. The method (Sections 5.1 and 5.2), procedure (Section 5.3) and results (Sections 5.4, 5.5 and 5.10) relevant to this chapter were first reported in Chapter 5.

The children's *coping behaviour* was also assessed. Each child was observed and his or her coping behaviour *showing an active interest* or *showing no interest* in the

blood test recorded. The observations lasted for four continuous 15 second intervals during the treatment phase of the blood test. Recorded observations have a possible range of 0 to 4. The data were not normally distributed but dichotomous; the two groups are defined as showing an *active interest* (n=23) and showing *no interest* (n=30) in the blood test. The method (Sections 6.2 and 6.3), procedure (Section 6.4.2) and results (Section 6.7) relevant to this chapter are reported in Chapter 6.

In Sections 8.7.1.1 and 8.7.1.2 the association between the children's coping (the coping strategies they reported to have used during the blood test and their coping behaviour) and whether a parent was absent or present during the blood test will be looked at in detail.

8.7.1.1 Parental presence and children's coping strategies

The *total number of coping strategies* used during the blood test, with a possible range of 0 to 10, were related to the parental presence or absence during the blood test. The Mann-Whitney U test for distribution free data and un-equal sample size was applied. No significant differences were found between the children's coping and parental presence or absence (z=0.730, p=.465, present n=29 and absent n=24).

Next, ten 2x2 chi-square tests were applied, providing information about associations between *individual coping strategies* and parental presence or absence. Yates' correction for continuity was applied. One coping strategy significantly differed between the two groups. The children, who reported having used *Emotion Regulation* 'I shouted screamed or got angry' or 'I tried to calm myself down' during the time their blood was taken, tended to be the children, whose parents were absent during the procedure, χ^2=4.46, p=.017, N=53.

This result from children not accompanied by their parents, showing they used *Emotion Regulation* during the blood test more than children whose parents were with them, was explored further. It was found, and is illustrated by Figure 8.4, that

children whose parents were absent during the blood test not only used the coping strategy Emotion Regulation more, but they also felt significantly less *nervous*, as measured by Kidcope, than children, whose parents were present.

A two-way analysis of variance was conducted to look at the effect parental presence and the coping strategy Emotion Regulation had on children *feeling nervous* during the blood test. There are significant main effects for both the *parental presence* or *absence* and feeling nervous and *Emotion Regulation* and feeling nervous; the former $F(1,49)=8.82$, $p=.005$ and the latter $F(1,49)=6.81$, $p=.012$. Children, whose parents were present during the blood test, felt more nervous than children, whose parents were absent, and children, who had used the coping strategy Emotion Regulation to help them deal with the blood test, felt more nervous than children, who did not use this coping strategy. In addition to the main effects of both treatment factors, there is a significant interaction ($F(1,49)=4.97$, $p=.029$). Whether or not a parent was present during the blood test and whether or not the child applied the coping strategy Emotion Regulation affected whether or not the child felt nervous. In reality, as illustrated by Figure 8.4, the significant effect of feeling more nervous during the blood test was due to one group, the children whose parents were with them *and* who reported to have used the coping strategy Emotion Regulation.

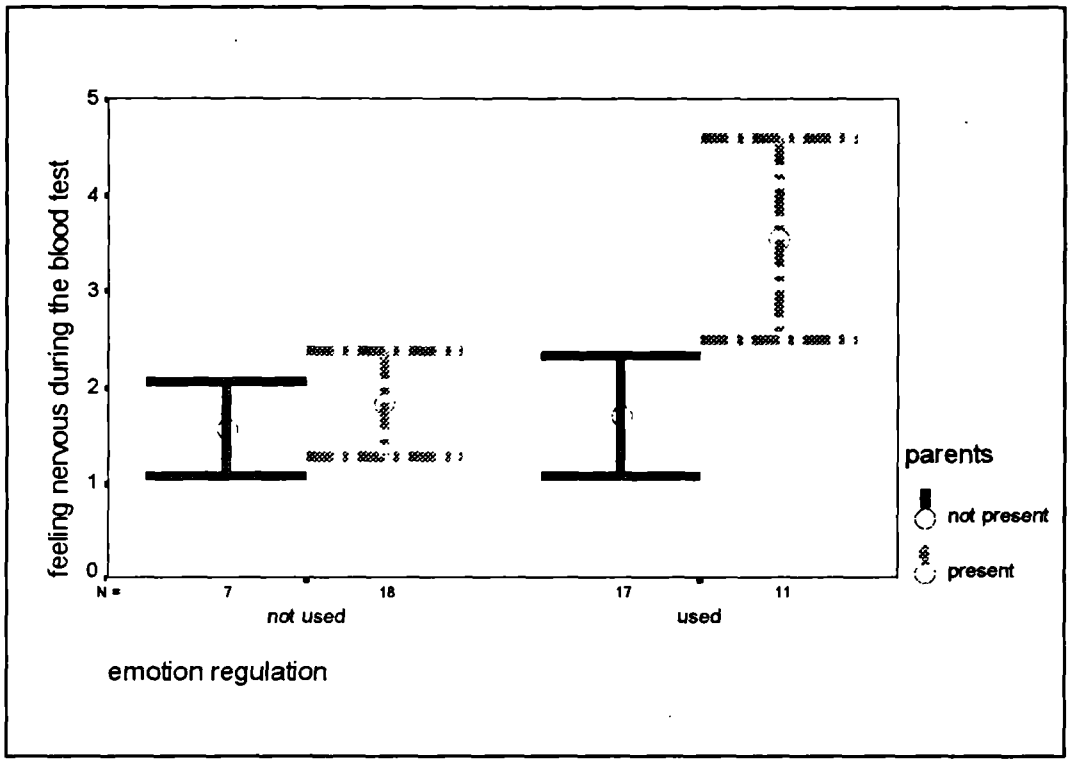


Figure 8.4 The relationship between Emotion Regulation, parental presence and feeling nervous during the blood test

However, further investigation into children's coping and parental presence during the blood test showed no significant difference between the two groups (*Social Withdrawal* χ^2=1.837, p=.098; *Problem Solving* χ^2=0.067, *p*=.590; *Wishful Thinking* χ^2=0.785, *p*=.242; *Social Support* χ^2=0.004, *p*=.952 and *Resignation* χ^2=0.091, *p*=.561; all N=53). The cell frequencies in four instances, *Distraction, Cognitive Restructuring, Self-criticism* and *Blaming Others* were so low that the chi-square test was not powerful enough to yield significant results. Fisher's exact test for probabilities for 2x2 tables was non significant.

8.7.1.2 Parental presence and children's coping behaviour

To explore the relationship between coping behaviour and parental presence a 2x2 chi square test was applied. No significant association was established between

children who were more or less interested in the blood test and whose parents were (n=29) or were not present (n=24) during the blood test; $\chi^2=1.14$, $p=.179$.

8.7.2 Parental presence: children's self-reported distress and their distress behaviour

As mentioned in Section 8.7.1, the Kidcope Checklist was completed three times by each child. It was related once to the previously observed blood test and twice to the self-chosen stressors in the everyday and illness related contexts. The self-reported distress element forms part of Kidcope and was completed during one-to-one interviews. The children reported three factors on a 5 point Likert-type scale: feeling *anxious/nervous, sad/unhappy* and *cross/angry*. In this part of the analysis it is the self-reported distress related to the blood test stressor that is explored. The method (Section 5.1), procedure (Section 5.3.2) and results (Sections 5.10 and 5.11) of the Kidcope distress element were first reported in Chapter 5.

8.7.2.1 Parental presence and children's self-reported distress

The distress scores assessed through the Kidcope Checklist for the blood test scenario and whether a parent was present or absent during this medical procedure were explored.

Children, who were on their own during the blood test, reported feeling less distressed than children, who had a parent with them. Figure 9.5 illustrates that children felt more nervous, a little more sad and more cross when their parents were present. The Mann-Whitney U test was used to look for significant differences between the two groups. The data are ordinal with a possible range of 1 to 5 for each of the three factors.

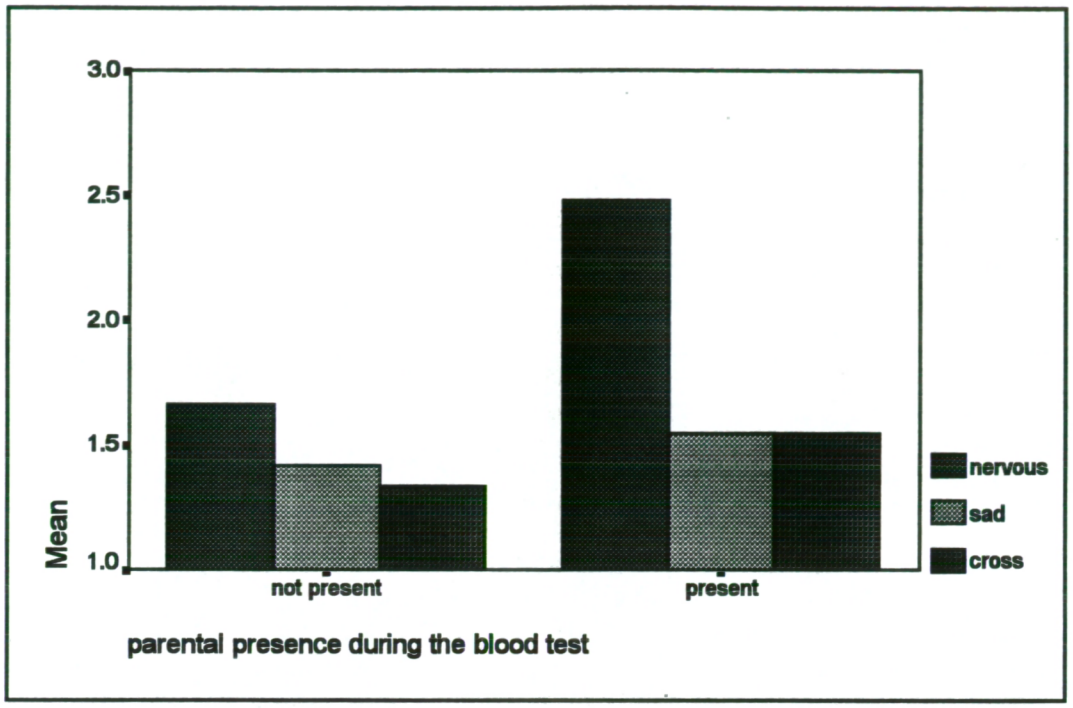


Figure 8.5 Self-reported distress related to the blood test stressor and parental presence or absence during the blood test

Statistical differences between the children's reported distress related to the observed blood test and whether a parent was present (n=24) or not (n=29) shown in Figure 8.5 were: *nervous/anxious* (z=1.88, p=.051); *sad/unhappy* (z=0.730, p=.465) and *cross/angry* (z=0.676, p=.499). As reported in Section 8.7.1.1, children who were without a parent reported to have felt significantly less nervous or anxious than children whose parents were with them throughout the procedure. This result suggests that parental presence influences the way children feel about having their blood taken. However, it should be remembered that on the whole parents are on hand to be with their child during this procedure and it may be that the children, who do not mind having a blood test, are the same children, who 'choose' to have their blood taken without their parents present.

8.7.2.2 Parental presence and children's distress behaviour

The distress behaviours recorded during the blood test (results were reported in Chapter 6) and parental presence or absence were compared and the findings are illustrated by Figure 8.6 and discussed below.

The children, who were without their parents during the blood test, did not show the *Restraint* distress behaviour (Figure 8.6). As it happened, in this study Restraint occurred only in instances where a parent was present. Fathers and mothers supported the medical staff during the blood test helping to avoid mishaps and additional pain. Therefore, when a multivariate analysis of variance was applied to compare the mean scores between the two groups Restraint was omitted during calculation, reducing the observed distress to six behaviours.

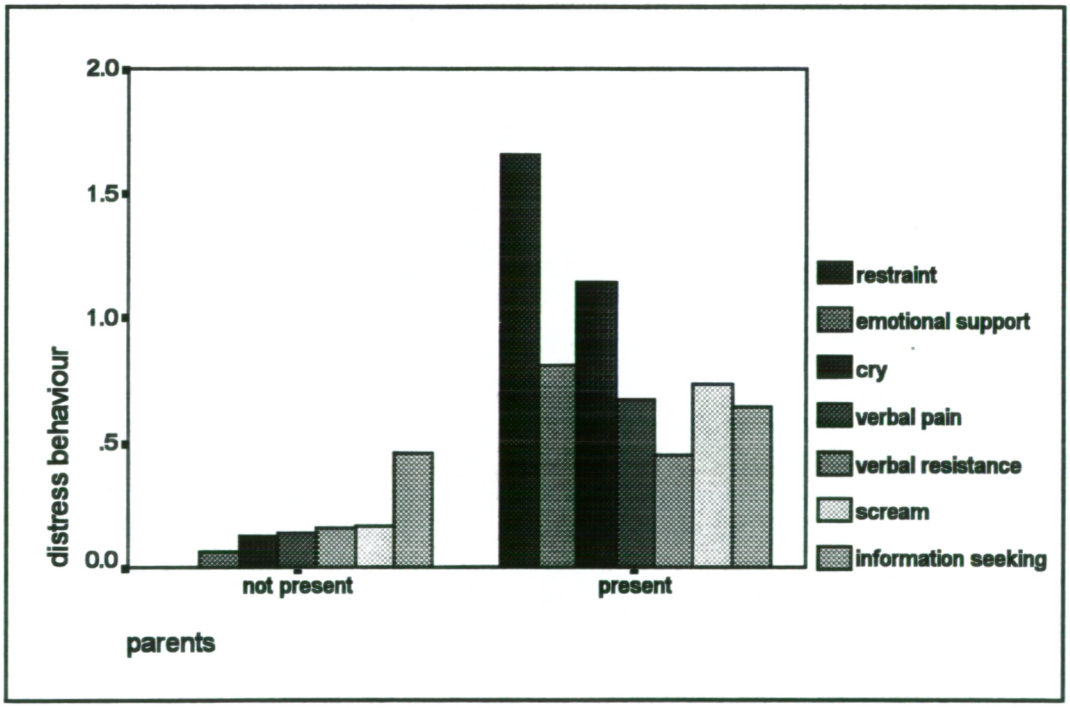


Figure 8.6 The children's distress behaviour and parental presence or absence during the blood test

The variable *distress* (within-subject) was made up of six factors as shown in Figure 8.6. These are Information Seeking, Cry, Scream, Verbal Resistance, Emotional Support and Verbal Pain. The variable *present* (between-subject) had two levels (parental presence and parental absence). Thus, there were six within- and two between- subjects and a MANOVA was conducted to look at differences between these groups.

The between-subjects effect was significant $F(1,51)=13.65$, $p=.001$ indicating an overall difference between distress behaviour and parental presence during the blood test. Children, whose parents were present, displayed more distress than children whose parents were absent. The Mauchly sphericity test was significant ($p=.014$) and therefore the Greenhouse-Geisser Epsilon was used to adjust the degree of freedom estimates. No significant effect was established between the six distress behaviours within each of the two situations $F(3.93,200.66)=1.29$, $p=.277$ (Figure 8.6). A significant interaction between distress behaviour and parental presence was not established $F(3.93,200.66)=1.30$, $p=.272$.

8.8 A summary of the results

Whether or not a parent was present during the blood test was recorded. Significant differences were established between the two groups. The children who used Emotion Regulation and who had a parent present during the blood test felt more nervous than the children who did not use this coping strategy and who were not accompanied during the medical procedure. The children whose parents were present generally felt more distressed and showed more distress behaviour than the children who did not have a parent with them. Hence, differences between coping, distress and parental presence or absence were confirmed.

As mentioned earlier these results should be interpreted with caution. This group of paediatric patients, all of whom suffered from a blood related disease, had previous

experience of blood tests and both the children and parents knew more or less what to expect. On the one hand, the differences may stem from the fact that children who are anxious about having their blood taken may specifically request a parent to be with them. On the other hand parental some parents may indeed influence their children's feelings and behaviour, providing sufficient security for them to feel free to display their distress.

In the final study, reported in Chapter 9, the family's social environment and the children's way of coping will be considered.

CHAPTER NINE
FAMILIAL INFLUENCE ON CHILDREN COPING WITH AN ILLNESS
Study 6

In this study two elements make up the *social climate of the family*: the family's social environment as measured by the Family Environment Scale (FES, Moos & Moos, 1986) and the family structure, whether the child is a member of a one parent or a two parent family. Members of the medical team often suggest that these two aspects of the family heavily influence children's coping with their illness. This chapter explores the relationship between the family social environment and the children's way of coping in part I, and the family structure and the children's way of coping in part II.

Study 6 part I

A total of 38 mothers, 27 from two parent families and 11 from single parent families, and 15 fathers from two parent families took part and completed the FES. These 53 parents were classed as main caregivers. They were parents, who spent most of the time caring for the ill child in the hospital, leaving the other parent and/or other members of the family to care for siblings at home. The children were either a member of a two parent family (n=42) or a single parent family (n=11). All the single parents were mothers.

Research questions:

> Is there a relationship between children's coping strategies reported in Kidcope and the three environmental dimensions (Relationship, Personal Growth and System Maintenance) as measured by FES?
>
> Is there a relationship between children's coping behaviour (taking an active interest in the blood test) and the three environmental dimensions as measured by FES?

Is there a relationship between children's distress behaviour during the blood test (OSBD) and the three environmental dimensions as measured by FES?

The method, procedure and results related to the core of coping as defined in this study have been reported in Chapter 5 (coping and distress *interviews*) and Chapter 6 (coping and distress *observations*). In the first part of this chapter results of the core of coping are looked at in conjunction with the family environment as measured by the FES.

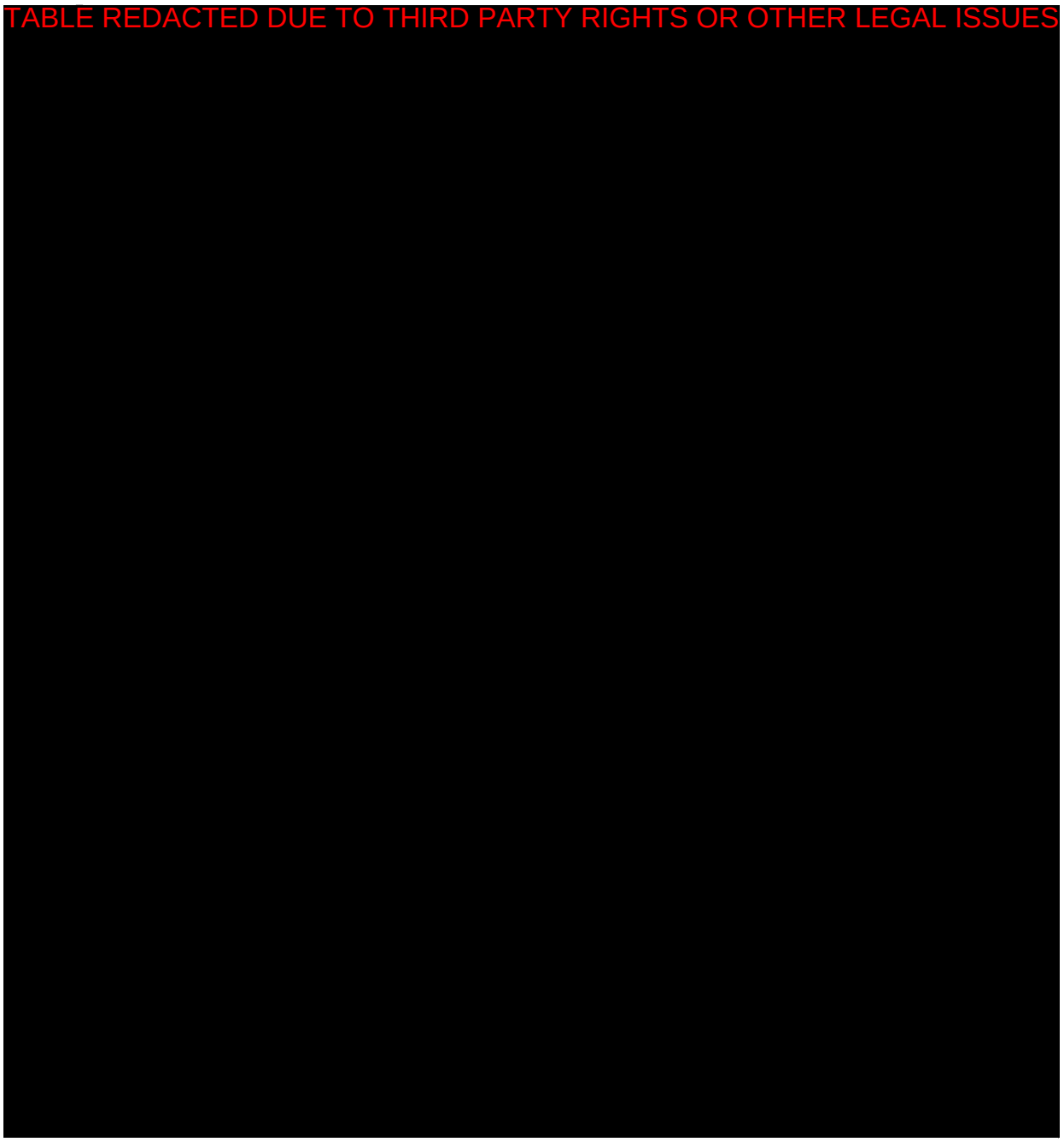
METHOD

9.1 The Family Environment Scale: a self-report measure

The Family Environment Scale is used to describe and compare *the social climate of the family*, contrast parent and child perceptions and examine actual and preferred family environment. According to Moos and Moos (1983) not only is it a solid, tried and tested instrument for researchers to use, but it also helps clinicians formulate case descriptions, and identify important issues in family treatment. It also provides information about the dynamics of family systems. Its scientific qualities are described below.

The FES has three forms: the Real Form which measures people's perceptions of their family environment, the Ideal Form which measures people's conceptions of ideal family environments and the Expectations Form which measures people's expectations about family settings. In this study it was the Real Form of the FES that was used and completed by parents of children with leukaemia or aplastic anaemia.

Table 9.1 The Family Environment Scale: ten subscales and three dimensions (Moos & Moos, 1986)



Moos and Moos developed the FES items from information gathered in structured interviews with members of different types of family. Information was gathered using several alternate questionnaire forms and this data formed the basis for the initial 200-item form of the FES. From the start the choice and wording of items was guided by the preformulated social-environmental dimensions. For example the degree of cohesion, the degree of achievement or the degree of organization within the family were considered. At the same time each item, according to Moos, had to identify an aspect of the family environment that could reflect the emphasis on interpersonal relationships, e.g. support between members within the family. This 200-item questionnaire was administered to 1,000 members of 285 families. The sample was mixed ethnically and socially to ensure that the FES would be applicable to a variety of family settings.

Five psychometric criteria were used to select the 90 items for the final form of the FES (Moos & Moos, 1986):

1) Items that showed a definite division should be as close as possible to 50-50 to avoid items characteristic only of unusual families.

2) Items should correlate more highly within their own subscale than with any other.

3) Each of the subscales should have an approximately equal number of items scored True or scored False to control for a routine response set.

4) The subscales should have low to moderate intercorrelations, showing stability yet permitting some variability between them.

5) Each item and each subscale should discriminate between families; an essential quality in the clinical setting.

The above criterion were met in subsamples of Caucasians, ethnic minorities and distressed families in the United States.

The latest version of the Family Environment Scale is a 90 item *TRUE - FALSE* self-report scale. The 90 items, some examples of which are given in Table 9.1, are positively and negatively keyed to avoid routine answers. They generate 10 subscales which in turn generate three dimensions. Each subscale is made up of nine items worded to reflect aspects of the social climate of the family. The ten subscales are defined and presented in Table 9.2 and make up the three dimensions; Relationships (three subscales), Personal Growth (five subscales) and System Maintenance (two subscales). The structure of the scale is best described in Table 9.1 and the dimensions are defined and reported in Table 9.3. An example is given in Appendix VIII.

Table 9.2 The Family Environment Scale: the subscales (Moos & Moos, 1986)

The ten subscales
1. *Cohesion:* The degree of commitment, help and support family members provide for each other.
2. *Expressiveness:* The extent to which family members are encouraged to act openly and to express their feelings directly.
3. *Conflict:* The amount of openly expressed anger, aggression and conflict among family members.
4. *Independence:* The extent to which family members are assertive, are self-sufficient and make their own decisions.
5. *Achievement Orientation:* The extent to which activities related to school and work are cast into an achievement-oriented or competitive framework.
6. *Intellectual-Cultural Orientation:* The degree of interest in political, social and cultural activities that forms part of the family.
7. *Active-Recreational Orientation:* The extent of participation in social and recreational activities which takes place within the family.
8. *Moral-Religious Emphasis:* The degree of emphasis on ethical and religious issues and values the family is involved in.
9. *Organization:* The degree of importance of clear organization and structure in planning family activities and responsibilities.
10. *Control:* The extent to which set rules and procedures are used to run family life.

Through factor analysis Moos and Moos found that the ten FES subscales assess three underlying sets of dimensions. These dimensions of different aspects of the family environment as measured by the FES are described in Table 9.3.

Table 9.3 The Family Environment Scale: the dimensions (Moos & Moos, 1986)

The three dimensions
I Relationship: is measured by the Cohesion, Expressiveness and Conflict subscales. These three subscales assess the degree of commitment, help and support family members provide for each other and the extent to which they are encouraged to act openly and to express their feelings directly. The amount of expressed anger, aggression and conflict among family member are also assessed.
II Personal Growth or goal orientation: is measured by the Independence, Achievement, Intellectual-Cultural, Active-Recreational and Moral-Religious subscales. These five subscales assess the extent to which family members are assertive, self-sufficient and make their own decisions. Also the extent to which activities are cast into an achievement or competitive framework, the degree of interest in political, social, intellectual and cultural activities and the extent of participation in social and recreational activities as well as the emphasis on ethical and religious issues and values are also assessed.
III System Maintenance: is measured by the Organization and Control subscales. These two subscales assess the degree of importance of clear organization and structure in planning family activities and responsibilities and the extent to which set rules and procedures are used to run family life.

9.1.1 Validity and reliability of the FES

Validity indicates that an instrument measures what it sets out to measure. Content and face validity were both built into the FES from the start. Information was gathered in interviews with members of different types of families. Definitions of the

constructs related to the environment of the family were formulated by the authors, who also claim that items were chosen on the basis of empirical criteria such as item intercorrelations, item-subscale correlations and internal consistency analyses. Finally, to increase conceptual clarity and minimize any item overlap, and to avoid ambiguity, each item was placed in only one of the three dimensions.

Reliability refers to the ability of a measure to produce consistent results. Moos and Moos reported internal consistency and intercorrelations related to the FES. The internal consistencies measured through the Cronbach's Alpha for each of the ten subscales are in the acceptable range from .61 to .78 (N=1067). The ten subscale scores were intercorrelated using data for 1,468 husband and wives and for 621 adolescent sons and daughters drawn from 534 normal and 266 distressed families. The intercorrelations ranged from r=.01 for Intercultural Orientation to r=-.53 for Conflict and were similar for parents and their children.

Test-retest reliability of individuals' scores for the 10 subscales were calculated for 47 family members in 9 families. The interval was eight weeks. Results of test-retest reliability were in the range of r=.68 for Independence to r=.86 for Cohesion. Remembering that changes in people's daily life as well as their family life do take place, the results of the FES repeated administration is an acceptable outcome accounting for 46% to 74% of the variance.

9.2 The Family Environment Scale: the procedure

The main caregiver from each of the 53 children completed the Family Environment Scale (Moos & Moos, 1986). Due to the seriousness of the illness parents tended to share the work between home and the hospital. The questionnaires were completed by 38 mothers and 15 fathers. Although differences between mothers and fathers and the social climate did not form part of the research questions, preliminary analysis

showed no significant differences. Therefore, the parents were treated as one group (N=53) throughout the second part of the result section.

All items were answered during one sitting in a quiet corner of the hospital. The researcher was near by to be able to help with any queries that might occur. Parents were given a choice of reading and ticking the items themselves or having the items read out by the researcher and ticking the items themselves.

9.2.1 The structure of the FES

The 90 items which make up the 10 subscales are presented in statement form. Some small changes were made to adjust the instrument to a British sample. For example: 'We believe in competition and "may the best *man* win" to 'We believe in competition and "may the best *person* win" and 'Family members make sure their rooms are *neat*' to 'Family members are sure their rooms are *tidy*'. Half of them score True (positive) and the other half False (negative) to control for habitual answering of the items.

The scale was analysed using the answer sheets and see-through scoring template provided with the FES. Ten raw scores emerged. These raw scores were converted into standard scores. The *standard scores* are based on research done by Moos and Moos (1979) on a normal family sample (N=1125). The conversion table of raw scores to the standard scores is given in the appendix. The standard scores as well as the mean and the median of the standard scores were used to analyse the data. A mean of the subscale standard scores, relevant to the three dimensions, was also calculated.

9.2.2 The question format

The test items are printed on a reusable form designed to be used with separate answer sheets. The participants were given a 2 point *TRUE for me* or *FALSE for me* forced choice format.

RESULTS

In Chapters 5 and 6 *the core of the children's coping* was looked at and reported in detail. *Individual differences*, including their self-esteem, experience with the illness, sex and age and its possible influence on coping were described in Chapter 7. In Chapter 8 the emphasis shifted from the child to the child and his or her parents. The associations between *parental factors*, the parents' presence or absence during a blood test and their general way of coping with their child's serious illness, and the children's coping were considered.

In this 6th and final study the issues are broadened still further from the child and his or her parents (Chapter 8) to the child and the social climate of the family.

9.3 The Family Environment Scale: social climate and its influence on children's coping and distress

Each FES subscale has a raw score with a possible range of 0 to 9, which is converted to a *standard score* as proposed by Moos and Moos (1986). The possible range of standard scores varies between the subscales, from Cohesion 1-68 to Conflict 32-81. However, the norm or population average as put forward by Moos and Moos lies around 50. A table converting the raw scores into standard scores is included in the appendix.

Although it did not form part of the research questions, preliminary statistical analyses were undertaken to look at whether or not the sex and age of the children and the time since the illness was first diagnosed were related to the FES. No significant differences were found. The children and their families (N=53) were therefore treated as a single group throughout this result section.

9.3.1 The FES: the subscales and dimensions

The median standard scores of the ten subscales for this sample are illustrated by Figure 9.1. They make up a family environment profile for this group of British families with a child with a serious or life threatening illness. As the possible range of the standard scores varies between subscales the median was used to present an overall picture. Item examples and the definitions are reported in Tables 9.1 and 9.2.

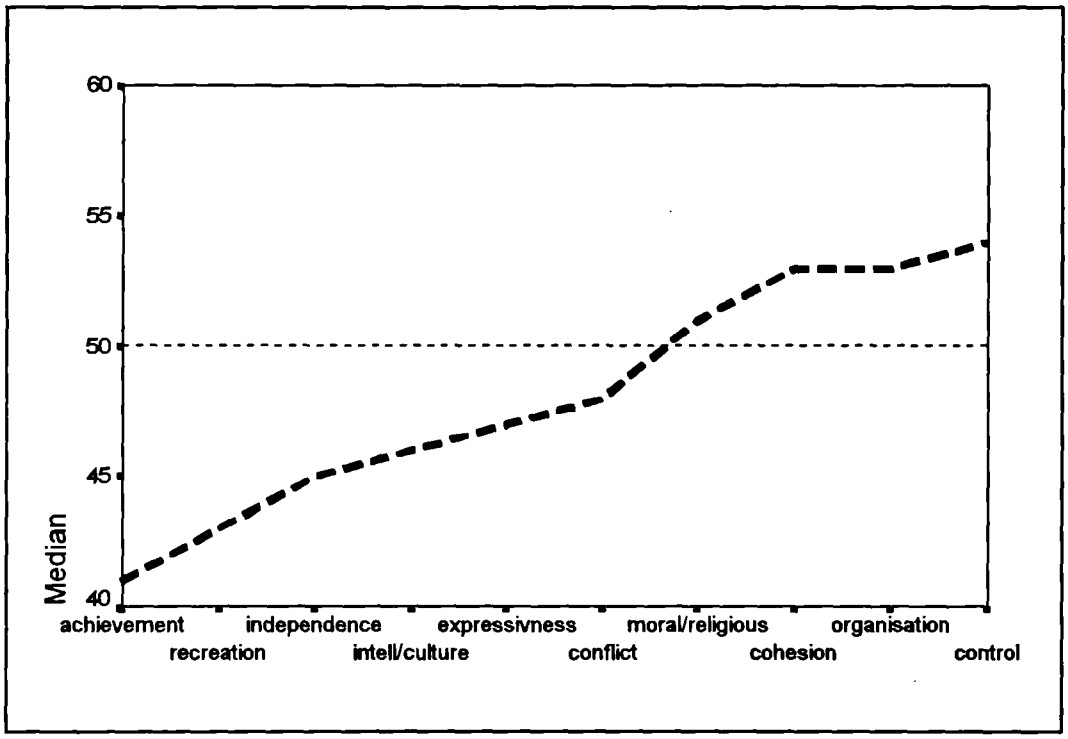


Figure 9.1 A profile of the median family environment (N=53)

Figure 9.1 shows little emphasis is put by this British sample of caregivers on the families' *achievement* in financial and scholastic terms or on their overall leisure activities including going out and playing sports or on the *independence* of family members, i.e., the extent to which they are assertive, self-sufficient and make their

own decisions. This result might be a direct reflection of the priorities set by families with a child with leukaemia or aplastic anaemia. At the same time, more emphasis is put on rules and the procedures used to run the family, the *organization* and structure in planning family responsibilities and the help and support members of the family provide for each other.

Table 9.4 Describing the ten subscales: results are based on the FES standard scores (N=53)

dimensions	subscales	min	max	median	mean	*SD*
I Relationship	1. *Cohesion*	16	60	53	48.87	11.26
	2. *Expressiveness*	21	73^	47	49.83	13.02
	3. *Conflict*	32^	70	48	48.59	11.08
II Personal Growth	4. *Independence*	3	62	45	43.17	14.69
	5. *Achievement*	16^	72^	41	44.45	12.85
	6. *Intellectual-Cultural*	23	70^	46	48.57	12.97
	7. *Active-Recreational*	21^	70^	43	45.72	12.62
	8. *Moral-Religious*	26^	72^	51	50.96	12.03
III System Maintenance	9. *Organization*	20^	70^	53	50.89	11.32
	10. *Control*	32	76^	54	52.55	10.33

^ Extreme scores: the minimum and/or maximum standard score for the subscale as reported by at least one main caregiver

As already mentioned, the subscale raw scores have a possible range of 0 to 9. They were converted using the conversion scale constructed by Moos and Moos (1986) and the population norm lies at 50. The possible range of standard scores varies between the subscales. For example, the lowest possible standard score for Conflict is 32 and the maximum score lies at 81. Due to the ceiling and floor effects both the median and the mean are reported.

The overall scores for Personal Growth are lower than the ones for Relationship. System Maintenance scores the highest and indicates that families with children with a serious illness find this dimension an important part of their family environment.

9.3.1.1 The FES: similarities and differences between family types

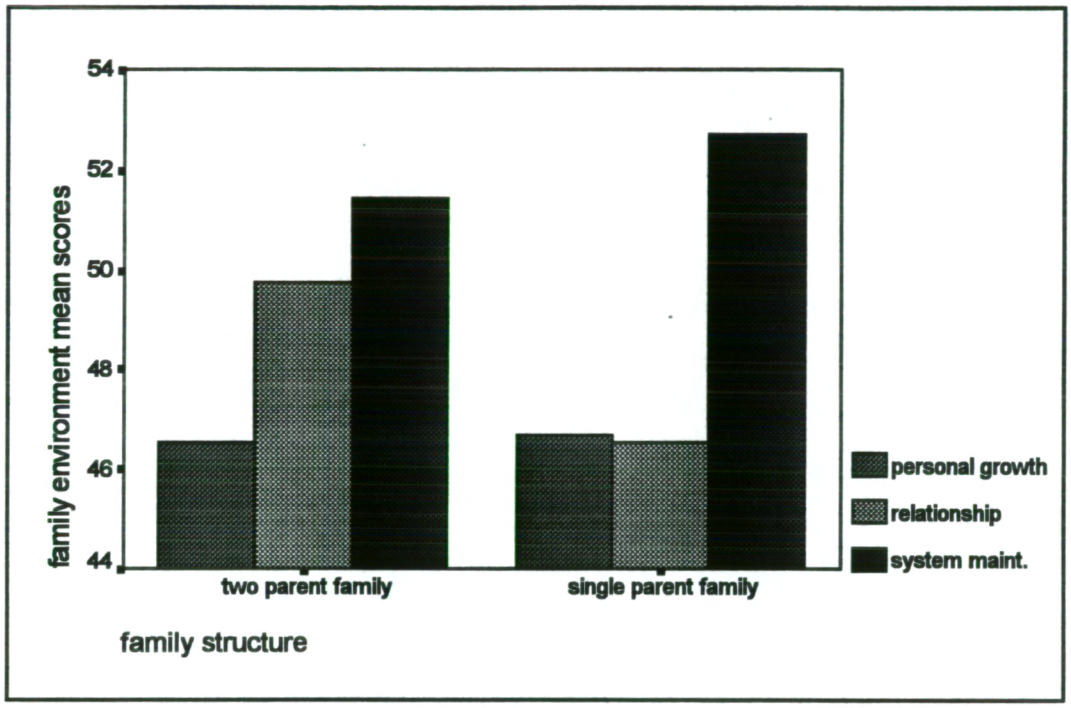


Figure 9.2 The social climate of the family: two parent (n=42) and single parent (n=11)

Figure 9.2 illustrates the mean standard scores of the three dimensions between the two types of families. The *Relationship* dimension was reported by two parent families to be more important than by single parent families. This result suggests the increased importance of the degree of commitment, help and support family members provide for each other and the extent to which they express their feelings directly in two parent families.

A MANOVA was applied to look for an association between the three FES dimensions (within-subject) and family structure (between-subject). The variable *environment* is made up of three factors, Relationship, Personal Growth and System Maintenance and the variable *family* of two factors, two parent families n=42 and single parent families n=11.

The between-subject effects for two parent families and single parent families and the FES mean scores ($F=1,51)=0.15$, $p=.697$ were non-significant showing no overall differences between family structure and the family environment. The Mauchley sphericity test was significant ($p<.001$) and the Greenhouse-Geisser Epsilon was applied. Variations between the three dimensions were established confirming the results represented by Figure 9.2. The within-subjects effect was $F(1.52, 77.60)=4.89$, $p=.017$. No overall interaction between the self-reported family environment dimensions and the family structure was established $F(1.52, 77.60)=0.84$, $p=.407$.

Although, as Figure 9.2 illustrates, variations between the family type and the social climate of the families do exist, these variations were found not to be statistically significant. The data from the two parent families and the single parent families will therefore be combined and treated as one group (N=53) throughout Section 9.4.

9.3.1.2 Subscales and dimensions and their relationship

The correlation coefficients of the ten subscales reported in Table 9.5 are overall low to moderate and not unlike the ones reported by Moos and Moos (1986). These results are related to each other to varying degrees. While variations exist, there are also some patterns. Two of the three subscales in the Relationship dimension are significantly related, one positive (Cohesion and Expressiveness) and one negative (Cohesion and Conflict). Even though these results are significant the explained variance is low at 13.7% and 9.6%. The subscales in the System Maintenance dimension are significantly related (Organisation and Control) accounting for 9.6%

of the variance. The five subscales which make up the Personal Growth dimension are loosely linked with correlation coefficients ranging from r= -.01 to r=.36, three of which are statistically significant.

Table 9.5 Correlation coefficients: intercorrelations between the three dimensions as measured by the FES (N=53)

subscales	1	2	3	4	5	6	7	8	9	10
1.	-									
Cohesion	-									
2.	**r=.37**	-								
Expressive	**p=.006**	-								
3.	**r=-.31**	r=.03	-							
Conflict	**p=.024**	p=.857	-							
4.	r=.14	r=.50	r=-.05	-						
Independ	p=.299	p<.001	p=.732	-						
5.	r=.03	r=-.12	r=-.14	r=-.12	-					
Achieve	p=.850	p=.400	p=.324	p=.405	-					
6.	r=.24	r=.24	r=.03	r=.25	r=.26	-				
Culture	p=.082	p=.082	p=.839	p=.069	p=.061	-				
7.	r=.30	r=.43	r=.20	r=.14	r=-.03	**r=.36**	-			
Recreation	p=.028	p=.001	p=.144	p=.307	p=.842	**p=.008**	-			
8.	r=.20	r=-.15	r=-.10	**r=-.37**	**r=.34**	r=.12	r=-.01	-		
Moral	p=.154	p=.278	p=.491	**p=.007**	**p=.014**	p=.400	p=.983	-		
9.	r=.01	r=-.11	r=-.14	r=-.23	r=.48	r=.17	r=.09	r=.11	-	
Organisat	p=.973	p=.428	p=.314	p=.092	p<.001	p=.216	p=.526	p=.456	-	
10.	r=-.27	r=-.54	r=.13	r=-.45	r=.40	r=-.04	r=-.25	r=.22	**r=.31**	-
Control	p=.053	p<.001	p=.343	p=.001	p=.003	p=.784	p=.069	p=.118	**p=.024**	-

Having reported the correlation coefficients from the subscales (Table 9.5) it is the correlation coefficients from the dimensions which will be examined. The *Relationship* dimension correlated significantly with both the *Personal Growth* and with the *System Maintenance* dimensions (r=.39, p=.004 and r= -.33, p=.016 respectively, both N=53). This result indicates that the more committed, helpful and supportive family members were with each other, the more important they found being assertive, self-sufficient and decisive. On the other hand the more committed, helpful and supportive family members were with each other, the less important they found organization and family structure in planning activities and responsibilities to be. There was no significant association between Personal Growth and System Maintenance (r=.10, p=.499, N=53).

It was concluded, from the results reported in Table 9.5, that the factor structure of the FES should be examined using the data from this special group of UK parents. A factor analysis, using the Principle Component method, was applied, to look at these data more closely.

9.3.1.3 The three dimensions: a factor analysis

First, a matrix of correlation coefficients (Table 9.5) was generated for the variable combinations. The determinant was .07 and it was therefore assumed that the matrix was adequately varied to proceed. The Kaiser-Meyer-Olkin measure of sample adequacy was .63 and the Bartlett test of sphericity was significant to p<.001. All three of these statistics confirmed that the data were suitable for further analysis. From the correlation matrix, using the Principle Component method, four factors were extracted.

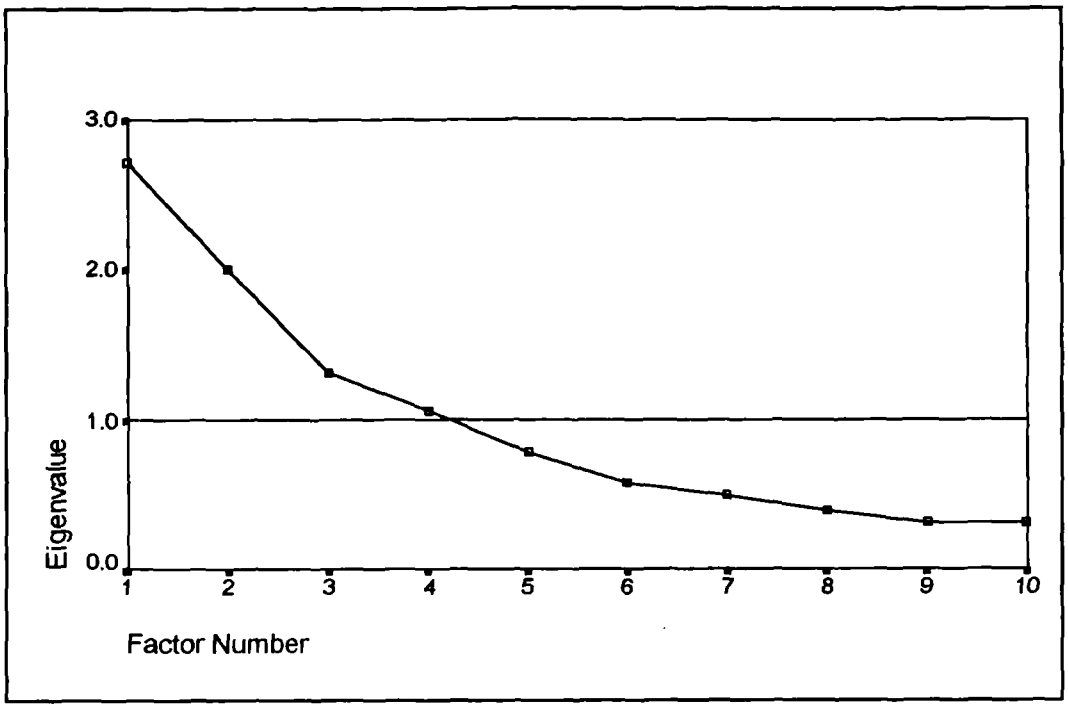


Figure 9.3 The factor scree plot: the ten FES subscales

The factor scree plot (Figure 9.3) indicates four factors with eigenvalues >1. A varimax rotation was applied to maximise the relationship between variables and factors. The loadings of the four observed factors were then compared with the three dimensions Moos and Moos established (Table 9.6).

Table 9.6 The rotated factor loadings (N=53)

dimensions	subscales	factor 1	factor 2	factor 3	factor 4
I Relationship	*Cohesion*	. 54			-. 62
	Expressiveness	. 69			
	Conflict				. 88
II Personal Growth	*Independence*			-. 76	
	Achievement		. 82		
	Intellectual-Cultural	. 63			
	Active-Recreational	. 82			
	Moral-Religious			. 81	
III System Maintenance	*Organization*		. 79		
	Control		. 53		

The subscales associated with the Relationship dimension form part of factors 1 and 4 and the subscales associated with the Personal Growth dimensions are seen to form part of factors 1, 2 and 3. The two subscales which make up the System Maintenance dimension remained together and form part of factor 2.

The three dimensions, Relationship, Personal Growth and System Maintenance, and the four 'new' factors and their loadings are reported in Table 9.6. From the results it can be deduced that the factors, which emerged from the factor analysis, are to some degree related to the original three dimensions put forward by Moos and Moos (1979). Factor analytic solutions are determined both by conceptual considerations and by aspects of the sample, the statistical procedures and criteria employed.

In this study the FES was completed by a small sample (N=53) and therefore the factors extracted are likely to be less reliable than those found by Moos and Moos. The comparison was made to see if similar patterns exist in this study where each

family has a member with a serious illness. Further analyses will be based on the original three dimensions.

9.3.2 The family environment: children's self-reported coping and their coping behaviour

One-to-one interviews were undertaken with the 53 children to find out more about the way they coped within different social contexts. The Kidcope Checklist was completed for three problems identified by each child: an everyday stressor, an illness related stressor and the blood test. The method (Sections 5.1 and 5.2), procedure (Section 5.3) and results (Section 4.10) relevant to this section are reported in Chapter 4.

Observations during the blood test showed 23 children took an active interest in the procedure and 30 children lacked interest in the procedure. As the data was not Normally distributed but dichotomous the two groups were clearly defined. The method (Sections 6.2 and 6.3), procedure (Section 6.4.2) and results (Section 6.7) relevant to this chapter are reported in Chapter 6.

Section 9.3.2 looks at the association between children's coping, their coping strategies they reported to have used and the coping behaviour they displayed and their family environment.

9.3.2.1 The family environment and children's coping strategies

The total number of coping strategies the children reported to have used when dealing with a specific stressor related to their illness and with the blood test (with a possible range of 0-10) and the three domains as measured by the FES were analysed using Pearson's product-moment correlation. From the six correlations, no significant relationships were found between the number of coping strategies used

within two contexts (illness related and the blood test) and the social climate of the family. Results ranged from r=.03 to r=.15 all N=53.

Differences between children having used a coping strategy, answered *yes,* and not having used a coping strategy, answered *no,* and the three dimensions of the Family Environment Scale were sought. The *t* test was applied except when the groups were small (n<10) in which case the Mann-Whitney U test was used.

The results of several statistical tests will now be discussed. To control for Type I error, Bonferroni's inequality was used to adjust the level of significance. However, this greatly increases the possibility of Type II errors hence significant pairwise comparisons at the conventional α=.05 level will also be reported. Given the increased likelihood of Type I errors these results should be regarded with caution.

Sixty tests were applied (two contexts, three dimensions and ten coping strategies; pairwise with an α=.05 level), and a summary of the results is reported in Table 9.7. None of these are significant with the Bonferroni inequality.

However, if the pairwise α=.05 level is used, some associations between children's way of coping and the family's social environment can be reported. It was found that children who used Distraction 'Did you do something like watch telly or play a game to forget?' and Wishful Thinking 'Did you wish you could make things different?' to deal with a specific *stressor related to their illness* come from families, who find Personal Growth a more important part of the social climate of their family than children, who did not uses these coping strategies. Children, who did not use Emotion Regulation 'Did you try to calm yourself down?', come from families where Personal Growth is a more important part of the social climate of the family than children, who did use the coping strategy Emotion Regulation.

Table 9.7 The family environment and children's way of coping

dimensions	coping strategy	ILLNESS *t/z* scores ^	*p* value	coping strategy	BLOOD TEST *t/z* score^	*p* value
Personal Growth	Distraction	*z*=2.17 n=8+45	. 029	Cognitive Restructuring	*z*=2.32 n=9+44	. 019
	Emotion Regulation	*t*=2.09 n=14+39	. 047	-		
	Wishful Thinking	*z*=1.98 n=6+47	. 048	-		
Relationship	-			Social Withdrawal	*t*=2.11 n=16+37	.042
	-			Resignation	*t*=2.27 n=22+31	.017

^ a *t*-test (n>10) or Mann-Whitney U test (n<10) was used according to the group size

When children talked about *dealing with the blood test* it was found that those, who did use Social Withdrawal 'Did you keep quiet about the problem?', come from families, who feel the Relationship dimension to be less important part of their environment than children who used Social Withdrawal. Children, who used Resignation 'Did you do nothing because the problem could not be solved anyway?', come from families who feel that the Relationship dimension is a more important part of their family's social environment than children, who did not use this coping strategy. And finally, children who used Cognitive Restructuring 'Did you try to see the good side of things?' are part of families who think that Personal Growth is more important to them than families where children did not use Cognitive Restructuring.

Overall, none of the differences were significant when Bonferroni's equality was adopted. Further there were no obvious patterns in the differences. However, there

were a few significant comparisons at $\alpha = .05$ level which may be of interest in future investigations.

9.3.2.2 The family environment and children's coping behaviour

Children's coping behaviour, taking an active interest in the blood test (n=30) or taking no interest in the blood test (n=23) and their family's social environment as reported by the main caregivers were investigated. A *t* test was applied to look for associations between children's coping behaviour and the three FES dimensions. No significant differences were found between the two groups and the FES: Relationship $t(51)=0.61$, $p=.544$; Personal Growth $t(51)=0.11$, $p=.910$ and System Maintenance $t(51)=0.29$, $p=.774$.

9.3.3 The family environment: children's self-reported distress and their distress behaviour

A self-reported distress element forms part of the Kidcope Checklist and was measured during one-to-one interviews. There are three factors each of which is answered on a 5 point Likert-type scale: feeling anxious/nervous, sad/unhappy and cross/angry. The distress score is made up by adding together the three factor scores. The possible range for the distress score is 3 to 15 for each of the contexts. The method (Section 5.1), procedure (Section 5.3.2) and results (Sections 5.10 and 5.11) are reported in Chapter 5.

The children's distress behaviour was assessed during a routine blood test. A structured observation schedule, the OSBD, was used. The method (Sections 6.4 and 6.4.1) and results (Section 6.5) are reported in Chapter 6.

Section 9.3.3.1 looks at the association of children's self-reported distress and the family environment and Section 9.3.3.2 at the children's distress behaviour and the family environment.

9.3.3.1 The family environment and children's self-reported distress

Children's overall distress, as described when reporting an illness related stressor and when talking about the blood test, was compared with the three dimensions reported by the main caregivers of the 53 families. The six correlations, Pearson's product-moment, which were found, showed no significant relationship between children's self-reported distress and the social climate of the family; results ranged from r= -.01 to r= -.16, all N=53.

9.3.3.2 The family environment and children's distress behaviour

The distress behaviour children showed during a routine blood test and the sort of family they are part of, as reported by the main caregiver, were looked at. Pearson's product-moment test compared the distress behaviour with the three dimensions of the FES. No significant association was found between the distress behaviour and the family environment. The results were: for the Relationship dimension r= -.04, p=.778, for the Personal Growth dimension r=.18, p=.189 and for the System Maintenance dimension r=.19, p=.190, all N=53.

The social climate of the family, as measured by the FES, did not make a difference that could be detected above chance in the degree to which children reported their own feelings of distress as measured by Kidcope and their distress behaviour, as measured by the OSBD.

9.4 A summary of the results so far

A profile of the family environment shows that these parents believe themselves to be both organised and controlled, maintaining their family system, and that they rated these factors more highly than factors related to personal development such as achievement, recreation and independence. This result points to their need for a

structured, ordered existence and a focus on the key issue; that is to say the survival and well being of a family member.

Possible associations were sought between the social climate of the family and the way the children coped. A large number of analyses were undertaken but few significant results were found. There were, however, some differences between coping strategies used by the children to deal with their illness related stressor and the blood test, and the Personal Growth and the Relationship dimensions reported by the main caregivers. For example, the children who used Resignation during the blood test come from families where the main caregiver reported the Relationship dimension to be more important than did the care givers of children who did not resign themselves to having a blood test.

Although there are few findings related to the family environment and the children's coping and distress, it would be unwise to assume that they are or should be independent of each other. As discussed in Section 8.4 it is likely that the lack of significant results may be due to the differences in what the instruments measured and how they measured them.

Study 6 part II

In part I of Study 6 the Family Environment Scale was discussed and the results related to the social environment of the 53 families. The possible influence of the family environment on the children's way of coping was reported in Section 9.3. In this second part analyses will focus on whether a child is a member of a two parent family or a single parent family and whether this influences children's way of coping with their illness and treatment. The results are reported in Section 9.5.

Research questions:

> Is there a relationship between children's coping strategies reported on Kidcope and family structure?
>
> Is there a relationship between children's coping behaviour (taking an active interest in the blood test) and family structure?
>
> Is there a relationship between children's self-reported distress on Kidcope and family structure?
>
> Is there a relationship between children's distress behaviour during the blood test (OSBD) and family structure?

Details of the method, procedure and results of the core of coping as defined in this study have been reported earlier in Chapter 5 (coping and distress assessed through *interviews*) and Chapter 6 (coping and distress assessed through *observations*). In Chapter 7 results of children's way of coping are associated with the structure of their family, i.e. two parent or a single parent family.

METHOD

9.5 The family structure: one parent and two parent families

During the initial meeting with the parents and the children, details concerning the family structure were recorded.

RESULTS

9.6 The family type and its influence on the children's coping and distress

9.6.1 The family type: children's self-reported coping and their coping behaviour

In this section an association between children from two parent or single parent families and their coping with a stressor related to the illness, with the blood test and their coping behaviour during the blood test was explored.

9.6.1.1 The family and children's coping strategies

The *total number of coping strategies* each child reported to have used when dealing with an illness related stressor and the blood test were looked at in the light of whether they were a member of a two parent or a single parent family. Due to the nature of the data, the children answered with a *yes* or *no* for having used a coping strategy; the Mann-Whitney U test was applied. The possible range was 0-10 for both contexts; illness related and the blood test. The coping strategy mean scores are used to illustrate the similarities in the illness context, and the differences in the blood test context between the family structure and children's way of coping (Figure 9.4).

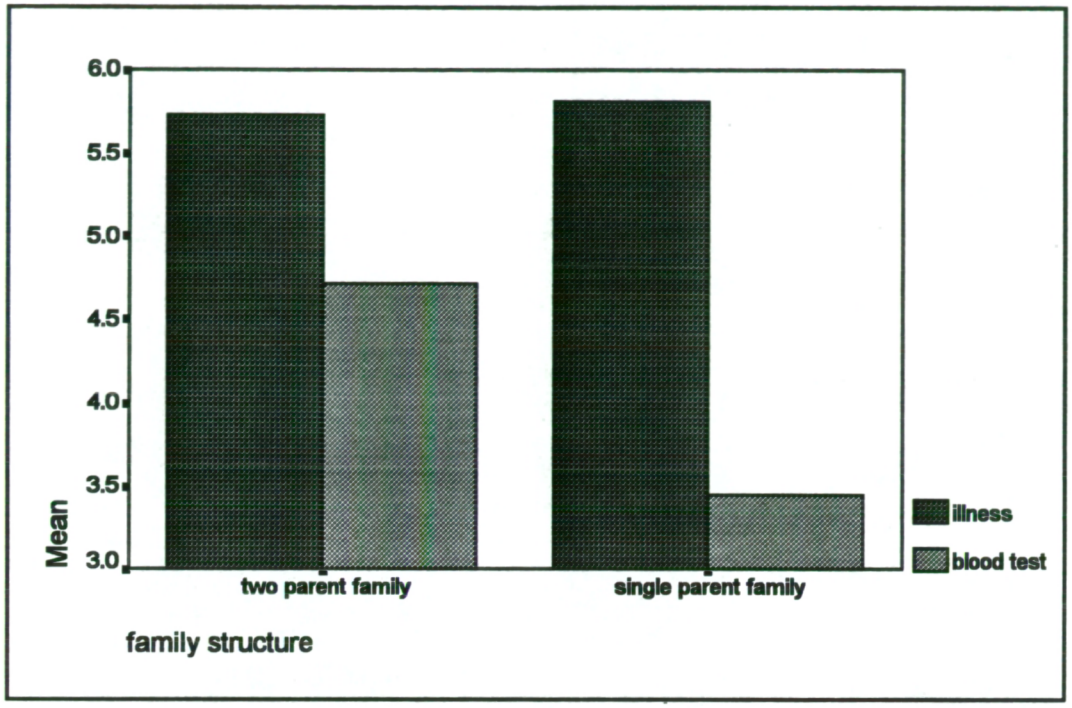


Figure 9.4 The family structure (42 two parent and 11 single parent families) and the number of coping strategies the children used in the two contexts

There was no significant difference between the children's coping in the illness related context and the family structure (z=0.10, p=.919, n=11, n=42). Nevertheless, children from two parent families reported to have used a higher number of strategies during the blood test than children from single parent families (z=2.12, p=.034, n=11, n=42).

9.6.1.2 The family and children's coping behaviour

A 2x2 chi square test was applied to examine the association between the family type, two parent families and single parent families, and children's coping behaviour, i.e. whether they took an *active interest* or *no interest* in the blood test.

A significant result was unlikely with one of the two groups being so small (n=11). The cell frequencies were too low to generate a powerful result.

9.6.2 The family type: children's self-reported distress and their distress behaviour

Results from the children's self-reported distress for the illness related stressor and the blood test, as measured by Kidcope, and their distress behaviour during the blood test, as measured by the OSBD, were compared with the family structure in which the children found themselves.

9.6.2.1 The family and children's self-reported distress

Self-reported distress was not related to family structure. The Mann-Whitney U test was applied to look for differences between the groups in the illness (z=0.85, p=.395, n=11, n=42) and in the blood test context (z=1.43, p=.154, n=11, n=42). The type of family the children are part of did not significantly influence their feeling of distress when they talked about an illness related stressor or the blood test.

9.6.2.2 The family and children's distress behaviour

During a routine blood test the children's *distress behaviour* was observed and recorded by the researcher. The results of these observations were compared with the type of family the children came from. A t test was applied and no significant differences were established (t(51)=0.62, p=.538) between the children from two parent families and the children from one parent families.

9.7 A summary of the results

It appears that the family structure did not make a difference that could be detected above chance in the way children coped with the illness related stressor and the blood test. Although children from two parent families reported having used more coping

strategies during the blood test, they did not feel more distressed during this medical procedure nor did they show more distress behaviour than children from single parent families. With only 11 children in one of the groups, these results should be looked at with caution.

Having reported the six empirical studies which make up this thesis their strengths and limitations will be discussed in Chapter 10.

CHAPTER TEN
THE DISCUSSION

The adult literature provides evidence that coping influences recovery from illness and that it moderates the relationship between stress and illness outcome (e.g. Monat & Lazarus, 1991; Lazarus, 1993a; Aldwin, 1994). This thesis explores coping in one paediatric group. It was designed to investigate the means by which children with aplastic anaemia and leukaemia cope with their illness. Some individual characteristics of the children were considered and were related to their coping with both the illness and with the medical treatment. The influence of the social environment of the family on the children's coping, and the way the parents coped with their child's illness and its influence on the child's way of coping, were also explored.

The choice of instruments and design was influenced by the theory of stress and coping developed by Lazarus and Folkman, especially their concept of coping which forms part of the transactional model. The present studies did not set out to test the Lazarus and Folkman model but to use it as the theoretical starting point for research questions and methods. In the process of data analyses certain limitations in the theory became apparent and these will be discussed later. These limitations reflect the difficulties of assessing a concept as complex as children coping with a serious illness.

The chapter begins with a discussion related to some of the instruments used to assess the children's coping. Three sections then follow on the influence of the context in which coping takes place, on the influence of individual differences on the children's coping, and on the influence of familial factors on their coping. In the final section theoretical issues are raised and discussed.

The revised Kidcope Checklist was shown to be a reliable and reasonably valid instrument and suitable for use in the assessment of coping in a paediatric group. Also a new coping measure was introduced for the first time in this thesis. It established clear differences between the children who showed an active interest in the blood test and the children who showed no interest. With regard to the influence of the context the results demonstrate that the context, and within it the type of stressor the children reported, is a major factor in their coping, and impacts on the amount of self-reported distress, the use of coping strategies and their perceived helpfulness. The children both individually and as a group applied a variety of coping strategies across the different contexts (common problem, illness related problem and the blood test). Results from both the self-report interviews and the observations showed systematic patterns in children's coping.

A weaker individual differences effect was also found. The children's feelings of self-worth were related to coping behaviour; active copers generally felt better about themselves than avoidant copers. With regard to the familial factors the children whose parents were present during the blood test exhibited more distress than children on their own. No significant differences were found between the children's coping and whether they were a member of a single parent or a two parent family.

Selected findings will be drawn from results reported in preceding chapters and issues related to these findings will be raised and discussed. This chapter also includes recommendations for future research.

10.1 Assessing ill children's coping

With the help of the revised and 'tested' Kidcope Checklist it will be possible for researchers in the future to start from a firm base and investigate and exchange findings related to the coping process in healthy school children in general and seriously ill children in particular. Kidcope has been put on a solid footing through establishing test-retest reliability for the distress element, the coping strategies and the perceived helpfulness. The newly devised colour-coded response strip (Figure 3.1) was shown to be reliable and valid and makes the distress section as well as the helpfulness section easier to assess.

It became apparent that Kidcope (Spirito *et al.*, 1988, 1991; Pretzlik & Hindley, 1993) is best administered on a one-to-one basis with the interviewer gently reminding the child to bear the one elected stressor in mind when answering the questions. As long as the Lazarus and Folkman model serves as a framework for coping research, the Kidcope frequency assessment should be answered with a simple *yes* or *no* and not on a Likert-type scale as several researchers have done. With the child homing in on one specific event, it makes no sense for answers to be given on a graded scale (Section 4.3.1). It has been shown that the Kidcope Checklist, although brief and simple to administer, is a complex instrument. Not without its faults, it nonetheless provides a reliable method of studying children's way of coping. In the past a variety of assessment measures (e.g. Patterson & McCubbin, 1983 and Tobin *et al.*, 1984 cited in Spirito *et al.*, 1988; Band, 1990; Gil *et al.*, 1991) were applied. A widespread use of the Kidcope Checklist by future researchers should allow coping data to be compared more convincingly. Systematic administration and uncomplicated, yet thorough analyses are necessary to establish a base from which coping mechanisms can be explained.

The strength of this instrument is that it has been shown to be not only reliable and reasonably valid but also theory driven - *situation specific, personal stressor and without reference to its immediate outcome* - and that it was designed with a clinical population in mind. Its brevity, although an advantage, can be criticised for the limited number of coping items. It can also be argued that the checklist should be extended to give more depth to each of the ten coping strategies assessed. However, bearing in mind that in order to achieve the optimum results a child will be asked to complete the checklist more than once during a single session, an extension to the interview would be likely to cause the child's attention to wander.

The Kidcope Checklist is also suitable for use as a repeated measure. Seriously ill children should be interviewed not so much at regular intervals but according to events associated with their illness. For instance, the child's first night in hospital, his or her first night back on the second visit to the hospital, his or her first night back on the third visit and so on. The scenarios would give clear indications of what children find stressful in similar contexts repeated over time; coping patterns might then emerge.

One strength of this thesis is that each child undergoing a medical procedure was systematically *observed* and subsequently *interviewed* about the observed events. The observations took place in the environment of the hospital. It would of course be unethical to set up a stressful situation purely for research purposes. However, it was possible to observe children while blood was being drawn. After the observation, the children reported how they felt about the proceedings and how they coped with the treatment. They also talked about how helpful they perceived their coping strategies to be. In previous research Hyson (1983) observed a wide range of behaviours of young children in a doctor's waiting room, unfamiliar territory for the children, but not a medical setting and certainly not one involving pain and discomfort.

The results of the observed distress behaviour and the distress reported during the interview were compared. The total observed distress scores and the total self-reported distress scores for the blood test were positively correlated. Children who showed more distress behaviour during the blood test reported having felt more distressed than children showing less distress behaviour. This finding has two important implications: firstly it validates the distress element of the Kidcope Checklist (Spirito *et al.*, 1988, 1991) for the first time and confirms the test actually measures what it sets out to measure - children's distress. Secondly it strengthens the validity of the OSBD (Jay & Elliott, 1986). The similarity between children's self-reported distress and their OSBD 'objective' scores provides welcome confirmation of their ability to accurately communicate their feelings in one-to-one interviews using Kidcope.

In future studies, using this combined interview and observation methodology, the researcher should consider interviewing the patient before as well as after the medical procedure, thereby providing a more rounded picture of the child's distress. Informal observations during the children's blood tests indicated that verbal and non-verbal interaction between the parent and the child and medical staff and the child play an important role in alleviating stress. In the future systematic recording of these interactions might yield interesting and valuable results.

Having validated the distress element of Kidcope, it was appropriate to relate the distress scores to the total number of coping strategies used. Children who reported feeling more *distressed* used a greater number of *coping strategies* to deal with a stressor *within* each context (common, illness related and blood test) but not across contexts. These significant relationships give added weight to the results of the Kidcope Checklist.

Avoidant and active coping has many definitions and is usually measured through self-report questionnaires and interviews (Peterson, 1989a). Gil, William, Thomas and Kinney (1991), for example, reported differences between children and adolescents with sickle cell disease who used more active coping strategies (diverting attention, calming self-statement) than children who reported using passive coping strategies (praying, hoping). The new coping behaviour measure devised for Study 3 assesses coping not so much as a process but more as a style (Section 1.1). As an additional measure, 'the taking an active interest in the blood test' coping behaviour category was added to the OSBD behaviour checklist. A child was defined as a coper with an *active interest* if he or she looked at the needle going into the skin and watched the blood coming out. A child who showed no interest in the blood test was defined as *lacking interest.* Clear differences were found between the active and avoidant copers. The children who showed an active interest were less distressed during the medical procedure than the children who showed no interest. These results endorse Gil *et al.* (1991) and Hubert *et al.*'s. (1988) findings as well as Peterson's (1989) summary of eight studies, all of which found that active copers, measured through a variety of methods, on the whole fared better than avoidant copers. For instance, Gil *et al.*'s found that less active copers had more emergency admissions, that they required more health care services, and were more distressed during painful episodes of their illness - sickle cell - than children who had been assessed as more active in their attempts to cope with the illness.

Although inter-rater reliability for the new coping behaviour measure was confirmed, the methodology needs to be repeated to verify reliability and to establish validity. One paediatric group should be observed during more than one blood test and these observations should be combined with self-report method to substantiate the coping behaviours. If active or avoidant coping behaviour is an observable coping style, then future research might benefit from measuring these styles more directly than through interviews.

The findings of the combined observation and self-report method, as well as establishing the avoidant and active coping behaviours, open up the scope for the use of observational measures in the medical setting. It is hoped that future research will continue to use systematic behavioural observation as well as interviews when studying children's coping.

In practical terms, some of the suggested improvements discussed in this chapter would have been possible to implement during data collection - observing more than one blood test for example. Unfortunately, once the original proposal had been accepted by the Medical Ethics Committees, any change from protocol was impossible. A copy of the proposal is included in Appendix II.

10.2 The influence of the context

In Lazarus and Folkman's (1984) definition of coping, coping refers to what the individual thinks and does within a *given situation* and the changes that take place as thoughts and actions occur. Coping is concerned with process and change and to look at the process involves looking at *what actually happens* and not what might happen within a context. Moreover coping is defined without reference to its immediate outcome, i.e. without reference to a tangible result or a visible effect.

It is assumed that children cope in a variety of ways subject to individual differences and situations. Researchers have traditionally looked for similarity and consistency of coping patterns or coping styles. Individual differences are often used as predictors. The age, IQ and temperament of a child have been found to affect coping outcomes (e.g. Jay & Elliott, 1984; Lumley *et al.*, 1990; Sylva *et al.*, 1993a), distress related behaviour for instance, but have not been found to be reliable predictors for assessing the actual coping strategies used.

As stated above, coping is a course of action employed by a child for each problem he or she encounters, i.e. each stressor within a context. In this study the self-selected stressors were described, and the coping strategies and their helpfulness were explored. Spirito *et al.* (1988, 1991, 1995), although basing their interview measure on the transactional model (Lazarus & Folkman, 1984), maintained the notion of consistency and predictability. In the next section, with reference to the three parts of the coping definition (*process* oriented, *contextual* and without referring to its immediate *outcome*), it will be argued that coping patterns do exist but that these patterns are influenced mainly by the situation, that is to say by the context in which a stressor is dealt with by the child, and less by his or her individual differences.

Children with a serious illness experience many stressful events, the most common of which is the administration of painful medical treatment. The children were asked how they felt (anxious, sad or cross) about the stressor they encountered. In Study 2 clear situational differences were established in the overall level of *distress* felt by the children. In answering Kidcope the children reported less distress when describing how they felt during the blood test than when they referred to the two self-selected stressors in the common and illness related context; why should that be? The differences may be purely contextual or they might be partly due to the methodology used. The blood test scenario was suggested to them by the researcher and was not selected by the children.

The majority of children dislike having to undergo a blood test (Richie *et al.*, 1990). Although for the children with leukaemia and aplastic anaemia it is a routine procedure, some of the children in this study made comments like "I start to worry about the blood test when I go to bed the day before I come here - no, I don't like it and sometimes I cry but afterwards I forget it quickly - I know it is good to have a blood test" and "It doesn't really hurt but I don't like it when I see the doctor with the needle".

During long periods on the ward informal observations showed that minor behavioural changes by the medical team enable children to become more relaxed about having their blood taken. For example, keeping to pre-arranged times, asking a child where he or she would prefer the blood test - in the finger, in the hand or in the arm - and taking account of children's meal times and social activities. Such decisions are taken solely by adults, and are easily understood by other adults but not by the children.

As with the amount of distress they reported, the children talked about having used some and not other coping strategies to deal with a stressor in each of the three contexts (everyday-life, illness and blood test). The content analyses of the stressors described by the children show that children selected different types of problems both *between* and *within* contexts; for example, when describing *illness related problems*, the majority of children mentioned a *physical* stressor within the medical environment such as "..losing all my hair, I worry what I will look like", "The Hickman line stops me going swimming with the other kids from school" or "The medicine makes me very sick and yesterday I threw up all day and all night". When talking about *everyday-life problems* the children mainly referred to *social* problems which took place in the school or home environment such as "I used to think K and B were my friends at school but now they tease me all the time and the other day they said very rude words to me" or "I miss my family a lot when I am in hospital, especially my brother". The *kinds of coping strategies* were used by the children according to the types of stressors they recalled.

The inconsistent application of coping strategies is best illustrated by a boy's reported use of *Resignation*. When confronted with an unavoidable injection he used Resignation, but when talking about falling behind in his school work this coping strategy was not employed. One of the girls reported using *Blaming Others* when

dealing with a group of girls teasing her, but when talking about the blood test she did not use this coping strategy.

The *number of coping strategies* used across the three contexts varied. For the common problem and the illness related problem they used overall more coping strategies than for the blood test. And not only did they use fewer coping strategies for the blood test, but they found the ones they did use more *helpful* than the ones used for both the common and the illness related problems.

In Study 2 the ten coping strategies and their perceived helpfulness were separated out from the findings mentioned above and *three main clusters of coping patterns* were identified. Firstly, when talking about an everyday problem the children used *Self-criticism* and *Blaming Others* more than when they talked about a problem related to their disease. They tended not to blame the doctor, who took their blood, for the anxiety they felt about this procedure nor did they blame another person when talking about being bored in hospital or not liking an x-ray. However, when talking about having a hard time with friends or siblings, *Blaming Others* was a coping strategy they regularly used.

Secondly, *Cognitive Restructuring, Distraction* and *Resignation* were mostly applied when talking about the blood test or an illness related problem and less when dealing with an everyday-life problem. Trying to see the good side of things was shown to be helpful when trying to alleviate the blood test or an illness related stressor - all three coping strategies were used and found helpful in the two medical settings.

Thirdly, five coping strategies were employed less by this group of children when they had to cope with the blood test, than when reporting on the elected stressors: *Wishful Thinking, Social Withdrawal, Problem Solving, Emotion Regulation* and

Social Support. The children knew that having a blood test helps the doctor help them.

Differences in the way the children used coping strategies for the *researcher-selected* stressor, the blood test, and the *self-selected* stressors, in both the common and the illness related contexts, make sense bearing in mind that coping depends on the individual's resources as well as the situation. On the one hand most but not all of the children would describe a blood test as a stressful event for them, on the other hand the two stressors selected by them would, by definition, always be stressful.

Spirito *et al.* (1995) is the only other study where Kidcope was used with chronically ill children and where self-selected stressors across two contexts were compared. In their study they again looked for similarities and ignored the relevance of differences between contexts.

In Study 2 coping with three stressors was described; two were selected by the children themselves and one was related to a medical procedure selected by the researcher. It was found that clear irregularities exist between the coping strategies the children used and the context in which they were used - both the total number of coping strategies and the individual coping strategies varied (Figure 5.3). As contextual effects have been established it is now appropriate to look for consistency in the way the children cope using exactly the same methodology with one important adjustment. In Study 2 and in past research (e.g. Spirito *et al.*, 1991; Pretzlik & Hindley, 1993; Spirito *et al.*, 1995) the contexts presented to the children have been so dissimilar (everyday-life and illness related stressor) that it was almost to be expected that copers would use different strategies across these contexts. However, by moving the contexts closer to each other (e.g. a problem with a friend, a problem with a sibling) and thereby increasing the possibility of similar stressor types, it is more likely that consistency of coping across two or more contexts will result.

In this study the contexts were brought closer together (the medical *procedure* and the illness *consequences* related stressors were taken from within the illness context) and it was possible to demonstrate that similar stressors do produce consistency of coping across situations. This exploratory analysis should be taken further in future studies.

Having considered coping and having found evidence to support the importance of the context in which coping takes place we will now turn to the coping approach with its emphasis on coping traits, sometimes called coping styles. This concept treats coping as a characteristic of the individual.

10.3 The influence of individual differences

Several analyses were conducted to determine whether coping is stable and liable to be affected by individual predispositions. Although links were found to exist between coping and self-esteem, age, sex and experience they were generally weak.

It is worth bearing in mind that the design of other studies reported in the literature often involve only one context, i.e. comparisons between contexts do not form part of their research questions and it is therefore more likely that individual differences between children will be found. Nevertheless, if we take this argument to its full conclusion and look at the analyses and the results reported in Study 4, we will see that the illness related and the blood test contexts were considered separately; yet results between the children's coping and their individual differences were not altogether convincing. One might therefore speculate that the methodology used and discussed below, as well as the nature of the sample - that is to say the seriousness and life threatening nature of the illness at the time of observation and interview -

might have 'knocked out' differences, that is to say created a ceiling effect, which are measurable in other children.

However, clear differences were found between coping behaviour and self-esteem, that is the way the children felt about themselves, as measured by the Self-Perception Profile for Children scale (Harter, 1985), and how they behaved during the blood test. The children who took an active interest in the blood test perceived themselves as more competent than the children who showed no interest in the blood being drawn out. The active copers' feelings of Global Self-worth were also significantly higher than the children who avoided watching the blood test. Although the theory of children's coping and self-esteem is rich (e.g. Compas, 1987; Lazarus, 1990) research data are sparse. Despite a large number of publications about children and their self-esteem, this is one of the few studies which combined children's perceived self-esteem and their coping behaviour observed during a real-life stressor (Pretzlik & Sylva, 1996). Bearing in mind that these findings are based on a special population, for reasons of good practice they are presumed to be of interest to both researchers and paediatric medical teams.

In Study 3 it was found that the older the children were the less distress behaviour they displayed. This result is in accordance with other research. Hyson (1983), for example, looked at 48 infants and toddlers aged 6 to 60 months. She found that younger children were more distressed than older children. Jay *et al.* (1983) observed 42 children between 2 and 20 years and found that the group of 2 to 7 year olds exhibited more distress than the 8 to 20 year olds. As children's distress behaviour tends to change with *age* not only in the 'amount' but also in the 'type' of behaviour, for example young children tending to Flail and Cry, the wide age band may have been a part contributor to the age effect found by Jay *et al.* (1983).

As in Jay *et al.* (1983) and Bradford's (1990) studies, no difference between *boys and girls* was found in the amount of distress behaviour observed. Nor was distress related behaviour significantly influenced by children's *experience* with blood tests. No significant differences were found between the children who had been ill for a shorter or a longer period of time. This result is in accordance with Richie *et al.* (1990) who observed a group of children during a fingerprick blood test and with Katz *et al.* (1980) who observed paediatric cancer patients during a bone marrow aspiration (BMA). Jay and Elliott (1984), however, did find that experience was a significant contributor to distress behaviour as measured by the Observation Scale of Behaviour Distress - the children who had been ill for longer coped better with the BMA.

Future studies should investigate children's distress behaviour within narrower age bands and should adjust the behaviour categories of the OSBD to older and younger children. Teenagers are less likely to cry and more likely to ask for information. They won't thrash about whereas a two year old will probably cry and flail.

Apart from the influence of self-esteem and age on coping and distress behaviour, findings were sparse. Having focused on individual differences in relation to the coping behaviour of the children, the association between their individual differences and the their self-reported coping will now be considered.

If individual characteristics influence children's way of coping as measured with an instrument based on the process of coping, i.e. the Kidcope Checklist, then comparing coping strategies used by individual children across contexts should yield significant agreement.

In Study 1, 32 children's coping was individually compared *within* each of the two contexts (everyday-life and illness related) over time. A significant association was established. After eight days most children reported having used the same coping strategies for the same stressor. This result shows that within contexts children's coping was stable.

In Spirito *et al.*'s (1995) study 177 children's coping was individually compared *across* two contexts. Moderately consistent patterns *across* an everyday-life stressor and an illness related stressor were reported. Their findings support the notion that coping is a process that differs somewhat within individuals across situations but that it also has some stability. However, in Study 2 no consistency *across* contexts was found. Fifty three children's coping was individually compared across the everyday-life and the illness context. The children's use of coping strategies varied according to the situation encountered. These findings contradict Spirito *et al.*'s (1995) results. The question therefore arises whether by using a bigger sample consistency and stability could be established. However, would an 'effective' coper really use the same coping strategies in such very different contexts?

Having asked the same children to describe how they coped with both an everyday-life and an illness related problem and having found no consistency across these contexts, we will turn to *age* and *sex* to look for situational variability.

In the present studies, as already stated, age, sex and experience of the illness did not significantly influence the children's coping patterns as measured by Kidcope. Peterson (1989) stresses the importance of taking the developmental level of the children into account, yet clear age differences have not always been found. An important contributory factor may be the way coping is defined and measured.

With Kidcope a child is encouraged to talk about a self-selected stressor that had worried him or her in particular. The stressor is described and then discussed in terms of what the children did and how it made them feel. Each child's coping pattern is measured according to his or her own 'tailor made' problem, and by doing so sex and age differences are minimized. For instance a seven year old boy expressed concern at being away from home whereas a 15 year old worried about getting dressed in the children's ward. Their stressor arose directly through thoughts and worries in their mind at that time. This method of assessing coping is in direct accordance with Lazarus and Folkman's definition and tells the researcher what had really worried them and not what worries children in general. This approach reduces developmental factors and makes the wide variety of stressors more difficult to compare. It does, however, give a more complete picture of a child and his or her stressors.

For example, Spirito *et al.* (1991) used two methodologies; first the children were asked to describe a self-selected stressor and were then presented with another stressor, this time a vignette about being 'grounded' by parents. For the everyday stressor, which the children had *elected* and described, there were no significant age or sex differences and the number of coping strategies they used. However, for the same group of children both age and sex effects were reported with the *preset* problem. Surprisingly, in their search for developmental factors, Spirito *et al.* seem to have missed the significance of their methodology and its use of a combination of self-selected and pre-selected stressors. In Band's (1990) study a group of diabetic children were *presented* with a choice of five stressors (e.g. diet, insulin injections). Once again sex and age differences were found in response to these preset stressors.

Children reporting on their self-selected stressors is an excellent way of looking at coping mechanisms and may, at the same time, control for some of the individual differences while emphasising the contextual importance of coping. However, it has

to be born in mind that children's choice of problems adds variability to the content analysis, i.e. different problems worry different children in different situations.

Although results reported in this thesis confirm the *situation* in which a stressor occurs and coping takes place to be a vital contributor to our knowledge of the coping process, the importance of a *child's characteristics* should not be disregarded.

So far in this chapter, a number of issues have been raised and recommendations for future research have been put forward. Having considered findings which help to describe how this group of children coped with their illness and treatment, and having related contextual differences to individual differences, it is the influence of the family on the children's coping that will be addressed in the next part of the discussion section.

10.4 The influence of the family

The family, according to Compas *et al.* (1992), stands out as an important element in the understanding of coping in a paediatric population.

Having already discussed the need to monitor verbal and non-verbal interaction between children and their parents as a way to investigate further how to reduce children's distress in such a stressful situation, one of the results reported in Study 5 points to the role parents play. Through observations during the blood test and interviews after the blood test it was found that unaccompanied children were less distressed than children who had a parent with them. Therefore a link between the way the children felt and behaved and whether their parents were present or absent was apparently confirmed. However, to assume from these results that parental presence directly affects children's behaviour may be premature. The children and

their parents involved in this study have had considerable previous experience with blood tests and know what to expect. One might argue that it may just be that the unaccompanied children were the children who were not alarmed by a routine blood test or that the absence of a parent inhibited their protest by reinforcing their determination to be brave.

However, experimental studies support the findings above. For instance in Shaw and Routh's (1982) study children aged 5 were randomly assigned to a condition with or without their mother present and were observed having an injection. The behaviour of those children whose mothers were present was rated significantly more negative than the group where the mothers were absent. Gonzalez, Routh, Saab, and Amstrong (1989) also observed children while they were given an injection. The children were once again randomly assigned to a condition with or without parental presence. Their study established that older children (5-8 years) were influenced by their parents' presence and showed significantly more distress behaviour, whereas the younger children (1-4 years) did not. Nevertheless, when consulted about future injections the older children's preference was overwhelmingly for parental presence.

Given the findings of these two studies it is reasonable to speculate that for the very young children at least it was less a question of a parent's absence or presence and more a matter of the children not having learned to conform to the convention of 'putting on a brave face'. In the future more experimental studies in this area should be undertaken and at the same time children should be asked how they feel about their parents being with them during a medical treatment and how and if their parents presence was helpful.

Parental presence is one of the contributory factors related to children's coping and distress during a medical procedure and should be taken into account during observations. Unfortunately although Richie *et al.* (1990) reported that half the

parents of all the children they observed during a fingerprick blood test were present, they omitted to study this factor in relation to levels of distress.

To conclude, this finding of children's distress as measured by the OSBD and parental presence can be linked with findings discussed earlier. Hence it can be said that the *older* children who *showed an interest* in the blood test and whose parents were *absent* during the treatment were less distressed by the blood test than younger children who showed no interest and whose parents were with them throughout the treatment.

A transactional model by definition is a multidirectional model, where child - parent, parent - child influence each other in the way they cope with a stressful situation. Throughout this thesis the child and the situation and the interaction between the child, the situation and his or her parents were kept as the focal point. Mothers as well as fathers took part and completed self-report questionnaires.

In the past, with few exceptions (e.g. McCubbin *et al.*, 1983; Eiser & Havermans, 1992; Eiser *et al.*, 1995), mothers' reactions received more attention than fathers' reactions to their child's illness. During time spent on the hospital wards and in the outpatient clinics by the researcher, anecdotal evidence showed that fathers play an important and interested role not just at home with the rest of the family but also while spending time with their child in hospital. There is a need to involve fathers in research, in order that we can better understand the processes by which mothers and fathers develop ways of managing and sharing the practical and emotional demands of caring for a child with a long term illness.

The mothers and fathers' from two parent families own perception of how they coped with their child's illness differed in so far as the fathers reported all four coping patterns to have been less helpful to them than they were to the mothers. Single

mothers found coping patterns slightly more helpful than the fathers and slightly less helpful than the other mothers. They all reported Medical Care followed by Family Support and Information as most helpful and Autonomy as the least helpful coping pattern. It is necessary to consider both mothers *and* fathers' responses to their child's illness, especially since, according to Eiser and Havermans (1992), there is increasing evidence of differences in their perceptions of the relative impact of their child's condition and of the helpfulness of different methods of coping.

Given that parental coping patterns are related to diagnostic groups (Eiser & Havermans, 1992), findings from a single diagnostic group need to be interpreted with care. Although the Coping Health Inventory for Parents was designed for parents of an ill population, it was a different population to the one who took part in this study. The original version (McCubbin *et al.*, 1983) was to be completed by parents of children with cystic fibrosis, a genetically transmitted disease that 'is always there'. Whereas the families who took part in Eiser and Havermans' (1992) study and in Study 5 were suddenly confronted by their child's illness and were possibly holding on to a justifiable hope for a positive long term outcome.

In previous studies the question of 'how do parents and children cope with an illness or disability' has been raised (e.g. Varni & Wallander, 1988; Varni *et al.*, 1996). But until the present study parents' perception of their own coping, and children's coping as reported by the children themselves and assessed through an independent observer, had not been combined. Children's behaviour had been observed by their mothers (e.g. Billing & Moos, 1983; Wallander *et al.*, 1988), but to minimise subjectivity, observations are best undertaken by trained, independent observers. Although of value, parental perceptions about the way they and their children cope with longterm illness should be supported by reports direct from the children; an approach which was adopted in this thesis.

In Study 5 both fathers and mothers took part. Their coping patterns were related to their children's way of coping with a self-selected illness related problem as well as the blood test. This combined approach only produced a few convincing results. However that should not disqualify it being used in the future.

Parents in general and parents of children with leukaemia and aplastic anaemia in particular constitute a major part of their children's world and vice versa. The lack of conclusive results in this study may be due to differences in *what* the instruments measured and *how* they measured it. The CHIP assessment of parental coping is limited in that it assesses no more than four coping patterns and in this case the coping patterns it did assess were related to how the mothers and fathers coped with their child's illness in *general* terms. By contrast the self-report and observational measures used to assess the children's coping were complex and looked at *specific* aspects of their illness (an illness related problem and the blood test). CHIP is ideal for providing a rough outline of parental coping with a child's illness but is too simplistic to permit the comparison of results with measures such as the OSBD and the Kidcope Checklist. If future studies use more sophisticated instruments than CHIP then the combined parent/child approach will yield worthwhile findings.

According to Eiser (1993) there is no causal link between the presence of a seriously ill child in a family and a subsequent divorce of the parents. However, given the incidence of divorce in the general population, many children with a life threatening illness are brought up in one parent families. It is therefore important that research includes both single and two parent families. In Study 6 distress and coping were considered between the children from one and from two parent families, and no significant differences were found between the two groups.

The social environment profile of the families who took part in Study 6 shows them to have placed most emphasis on *control* and *organisation*. Set rules and procedures

were used to regulate daily family life, and a clear organisation and structure in planning activities and responsibilities was important to them. *Achievement*, involving competitive performance at both school and in the work place, was relegated to the lowest level of importance, and *recreation*, that is the social and leisure activities which take place within the family, was not rated much higher either. What we do not know is whether the social environment of a family changed as a result of their child's illness or if it was like that prior to the onset of the illness.

This thesis was designed to describe children's coping with their illness and treatment and to explore factors which influence their coping. In Studies 5 and 6 parents' perception of their own coping (as discussed in Section 10.5.2) and the family environment and the children's coping as reported by *the children themselves* and assessed through *an independent observer* were combined for the first time. Moving away from the core of the children's coping (Studies 2 and 3) to their coping and individual differences (Study 4), then on to their coping and parental coping, and to their coping and the social climate of the family (Studies 5 and 6), links become progressively weaker.

It is too early to conclude that familial factors have little influence on children's coping. The few significant results related to the children's coping and the social climate of the family should be interpreted with caution. There may be two reasons or a combination of the two reasons for this weakness. Firstly, the sample was small and a larger sample of children and parents might yield more robust results. Although all the children suffered from a serious blood related disease, and were observed and interviewed by the same researcher within the hospital setting, and although they were found to be more or less homogeneous, we should remind ourselves that the patient intake in a London teaching hospital reflects the population of the capital - leukaemia and aplastic anaemia know no social or cultural boundaries. Secondly, the results may be due to the design of the studies. The Family Environment Scale was

selected with the Lazarus and Folkman (1984) transactional model of stress and coping in mind. Although it is reported to be a solid and well tested measures, it may be too limited in what it assesses. As one moves further away from the core of children's coping, influential factors become increasingly complex and perhaps require more sophisticated methods of assessment.

10.5 The way forward

Throughout this chapter a number of suggestions for future research have been proposed. Although no quantum leaps have been made, material was presented that will help to bridge and fill gaps which currently exist in our knowledge and understanding of children's coping with a serious illness. In this section two additional issues are considered: the weakness in the design of Studies 5 and 6 and how they might be improved for future work on children's coping and familial factors, and the shortcomings of one part of Lazarus and Folkman's definition of coping and a suggestion as to how it might be enhanced by the further study of coping in paediatric groups.

Taking the weakness in the methodology of Studies 5 and 6 first, children's coping was described and related to parental and family influences and with hindsight the design of the two studies falls short of what is required both in terms of concept and measurement. Children's coping with their illness and a medical procedure was measured in specific detail, whereas the familial factors including parental coping and the social environment of the family, were measured in more general terms. A degree of incompatibility therefore exists between what was measured and how it was measured.

For instance, Kidcope (Study 1) and the OSBD (Sections 6.1 and 6.5) are known to be reliable instruments and to have reasonable validity. It was established that the FES (Section 9.3.1) measured, in this population at least, what it set out to measure. However, when reflecting on the conceptual issue of the association between children's coping and familial factors, it becomes clear that more thought needs to go into this area as the level of complexity is such that the instruments used here for assessing parental and environmental factors are too restricted and lacking in sophistication to provide meaningful information about children coping with a serious illness and the influences families have on their children's coping.

As one moves from the individual child and the immediate and direct influences on his or her coping, such as the context and individual differences, to the family, the more complex the influences become (referring to Figure 4.1). Research measures need to be more, not less sophisticated to provide accurate assessment of the nature and strength of these influences and of the interactions and transactions between the child's coping and familial factors.

Improved methodology could provide increased information about the link between children's coping and familial factors. Firstly, it should be remembered that coping is a complex concept. Not only does the assessment of children's coping and familial factors have to be matched with compatible methods but care must be taken in deciding what the instruments actually measure and how they measure it. Secondly, it needs to be stressed that the three methodologies used here - parents' perception of their coping with the child's illness, children's coping as reported by children themselves, and children's coping assessed through an independent observer - should all be combined to improve on past studies (e.g. Billings and Moos, 1983; Varni *et al.*, 1996). Thirdly, to do this fundamental research question justice it will be necessary for further studies to be conducted on a larger scale - not just in terms of

the refinement of assessment but also increasing the number of families and the funding and human resources involved.

Turning now to the second issue, the Kidcope Checklist designed by Spirito *et al.* (1988, 1991) is based on the Lazarus and Folkman (1984) definition of coping. That is to say coping is defined without taking effectiveness into account, and is not immediately assessed as to outcome. Lazarus and Folkman freed the concept of coping from judgement of effectiveness, and as a result of their work *any* effort an individual makes in reaction or response to a stressor is now termed 'coping'. By considering how an individual copes with a stressor in a specific context without the need to refer to the outcome a more complete picture of his or her way of coping can be formed.

However, this much improved understanding of coping has left clinicians without obvious 'guide lines', and to that extent the Lazarus and Folkman definition is deficient in that it provides no theoretical structure to look at the effectiveness of coping, i.e. its outcomes. In the clinical setting for example, when talking about recovery from illness, reducing stress in hospital, helping needle phobic children cope with the procedure or encouraging them to learn more about their treatment, outcome measures would be helpful.

Apart from the necessity for researchers to understand how children cope in general, it is of interest to both them and clinicians to know how they can assist children with long term illness deal with specific stressful situations. As mentioned above the coping definition states that no reference is made to its immediate outcome for any discrete instance. Lazarus and Folkman consider coping as any effort made by an individual to manage a situation and are not concerned with the 'success' or 'failure' of those efforts. Therefore as long as no certain predictors are found, and if Kidcope is to be used as the basis for assessing children's way of coping with their illness and

illness related stressors, careful reflection is called for before designing any form of intervention program for these children.

It might nonetheless be appropriate to help children with long term illness make distinctions between a *global* stressor, the illness, and a *specific* stressor, hairloss, and between *changeable* aspects, reading a book or playing a game to alleviate boredom on the ward, and *unchangeable* aspects, having to take foul tasting medicine. In other words the child cannot do anything about the illness as a whole but if the stressor could be reduced to manageable proportions - i.e. from the general to the specific and personal - he or she may be able to devise and apply helpful coping strategies to deal with the problem. Figure 1.2 clarifies this idea.

While assessing children's perceived helpfulness on the Kidcope Checklist, a limited attempt is made to look at the effectiveness or outcome of coping in a specific context. When a coping strategy is reported to have been applied, the child is asked 'How much did it help?' In this thesis the children did not automatically find a coping strategy they used helpful (Figure 5.3). Due to the nature of the data it is problematic to compare the results with other findings. The fact that helpfulness is scored *only* when a child reports having actually *used* a coping strategy to deal with a specific stressor results in missing data. In future attempts to look at effectiveness of coping this approach should be extended. Through semi-structured interviews children should be asked about their perception of the effectiveness of behavioural or cognitive efforts made by them when coping with a specific stressor, and the results of the interviews should be combined with nurses reports and physiological measures.

The next step is to extend theory to include the effectiveness of coping. While accepting the significance and usefulness of the transactional model of stress and coping as it stands (Figure 1.2), conceptual thinking about coping needs to be advanced for theoretical as well as for practical reasons. An addition to the structure

of the transactional model, and coping within it, has to be established; i.e. one which includes the concept of effectiveness in coping.

In this proposed new area of research it should not be forgotten that coping is a process and that the assessment of effectiveness should be linked to children's coping patterns and coping strategies. That is *not* to say that we return to 'judgemental' assessment of coping as was done before Lazarus and Folkman, rather that we need to think of constructive ways of assessing the effectiveness of coping strategies used and so provide a framework for clinicians. A simple case study approach could be adopted and carried out by trained, objective clinicians or alternatively an experimental approach could be seriously considered for the first time in this field of study.

10. 6 The children: a personal note

This thesis would not be complete without a few words about the children who took part in the studies. Many people have suggested that being with children who are desperately ill would be a solely sad experience. If only they knew!

Some of the children were wise and brave, many were bored and sometimes sad, and others were resilient, strong and very funny. Their beds were islands of personal space in a changing community, where laughter echoed and friendships were made, where videos were watched and Game Boys played, and where kettles were kept on the boil and the medical teams cheerfully hustled and bustled. On the ward there was a mutual feeling of support and understanding and the children felt 'normal', even when linked from the Hickman line to the 'robot', or when loosing all their hair.

I am grateful to the children for teaching me to be happy with my lot, and for knowing David who kept me informed about Home and Away. I am grateful too to Emma who is well now and who writes regularly telling me all about the Child Development GCSE she is taking, to Mitali for her non-stop chatter and for trusting me with her fear of needles, to Pat who asked me as her special friend to Jamie's funeral and to Meron who wanted me to sit with her gently rubbing her back as she was gasping for her last breaths.

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APPENDICES

APPENDIX I

THE PROPOSAL FOR THE SCHOOL STUDY

The proposal, the Kidcope Checklist and the colour coded response sheet as well as a cover note were sent to the three London primary schools who took part in Study 1

THE SCHOOL STUDY PROPOSAL

Measuring children's coping

The Kidcope Checklist, the instrument used in this study, was developed in the USA by Anthony Spirito (1988) and is modelled on the 'Way of Coping' questionnaire for adults (Folkman & Lazarus, 1984). It has been used with children from 9-18 years. There are two versions, Kidcope for Younger Children 9-13 year olds (Spirito *et al.*, 1991) and Kidcope for Older Children 13-18 year olds (Spirito *et al.*, 1988).

The main aims of the study are:

To adapt Kidcope to younger children by producing a colour coded response scale and modifying the language of the checklist to suit a British sample.

To compare the responses of children using the colour coded response scale and the original Kidcope where words are used and to validate the colour coded response scale.

Test-retest the modified Kidcope to suit a younger British sample.

The children:

Children from a London primary school will take part. There will be a total of 32 children, a mixture of boys and girls; 16 aged 7-8 and 16 aged 9-10.

The instrument:

The Kidcope Checklist is completed rating the answers to the individual scenarios. Each child is asked to recall and talk about a recent *common* or everyday problem and an *illness* related problem, and rate the degree of distress on a 1-5 Likert-type scale from *not at all, a little, somewhat* to *a lot* and *very much.*

A colour coded response sheet has been developed to help children report on the three factors which make up the distress element of Kidcope:

"*Did that time* (related to the described scenario) *make you feel*
nervous or *anxious*? **orange**
sad or *unhappy*? **blue**
cross or *angry*?" **red**

The checklist consists of 10 coping strategies. Each of the ones reported to have been used (yes or no) is rated as to how helpful it was perceived to be. "*How much did it help*?" from *not as all* and *a little* to *a lot.* Helpfulness is scored on a 1-3 Likert-type scale. To make the answer visual and therefore easier for the children, a **green** colour strip was developed and will be applied.
A copy of the *Kidcope Checklist* and the *colour coded response strip* are enclosed.

The procedure:

The children will be asked to complete the Kidcope Checklist twice (changing the order, common then illness and vice versa) on two separate occasions during one-to-one interviews conducted by the same researcher (Table 1).

Table 1 Proposed procedure (N=32)

Sessions	16 children 7-8 years old		16 children 9-10 years old	
1) Day 1	8 using the colour strip	8 using words only	8 using the colour strip	8 using words only
2) Day 7	8 using words only	8 using the colour strip	8 using words only	8 using the colour strip

The colour coded response strips will be counterbalanced by the use of words only during sessions 1 and 2 (for *validity* and *reliability*).

During **session 1** the child will be asked to choose and recall a personal stressor related to a common problem and an illness problem, the order of the stressor type change.

During **session 2** the researcher will remind the child of the stressors he or she talked about during session 1 and Kidcope will be completed twice more with reference to the same stressors (reversing the order).

APPENDIX II

APPLICATION TO THE TWO ETHICS COMMITTEES

The Local Research Ethics Committee for
the Wandsworth Health Authority (1)

The Local Research Ethics Committee for
the Barts NHS Group (2)

27 August 1992

Dear Mrs Boyce,

As discussed on the telephone last Monday, please find enclosed 15 copies of the ethics committee application form. I have attached to each copy two of the instruments, both which are central to the study, with the view that the panel might find them interesting. As you suggested the details of the other questionnaires are included in the list of references.

My research supervisor Dr Peter Hindley, is still on holiday. As I am going to a conference myself I will be sending him the form (last page) to sign and he will get the original and 14 copies to you towards the end of next week. I do hope that this will not cause you too much trouble.

Yours sincerely

Ursula Pretzlik

c.c. Dr Peter Hindley

Text cut off in original

TABLE REDACTED DUE TO THIRD PARTY RIGHTS OR OTHER LEGAL ISSUES

TABLE REDACTED DUE TO THIRD PARTY RIGHTS OR OTHER LEGAL ISSUES

TABLE REDACTED DUE TO THIRD PARTY RIGHTS OR OTHER LEGAL ISSUES

TABLE REDACTED DUE TO THIRD PARTY RIGHTS OR OTHER LEGAL ISSUES

TABLE REDACTED DUE TO THIRD PARTY RIGHTS OR OTHER LEGAL ISSUES

VHERE WILL THE RESEARCH BE CARRIED OUT? (Name of Laboratory/Hospital/Other). Give name and ress of reponsible organisation if not St George's Group or Medical School.

the ward and out-patients, St George's Hospital, London SW17; and will be extended other hospitals.

ECRUITMENT OF SUBJECTS : How many will you need, and will they be patients, staff, students, or other unteers? How will they be recruited?

Subjects 30 paediatric patients

Controls None

Criteria for inclusion or exclusion of the recruits: See 'design of study'

the first instance, during a period of 18 months, it is anticipated that 30 or more tients will be studied. The research will be expanded to other hospitals.

ojects will be recruited through weekly liaison with medical staff on the ward.

the possibility of your subjects being pregnant relevant to your study? ~~Yes~~/No

If studying patients who are not your direct clinical responsibility, has the permission of the consultant in charge been obtained?
Dr Davies and Dr Bell have agreed the design and promised cooperation.

TUDENTS : Will medical/nursing students be involved as volunteers? ~~Yes~~/No

Not applicable.

o, an explanatory letter and copy of this form must be sent to the Dean or to the Executive Principal of Nurse ication/ Maternity Services Manager, as appropriate.

e sent _____

ase attach the letter of approval to this form or forward as soon as possible.

. a) Volunteers must be over the age of 18 years.

b) Investigators must ascertain that participants are not involved in any other studies which would be either dvantageous to their own health or the benefit of the study.

c)All medical students taking part in any study must register with the Cash Office, Hunter Wing, St. George's pital Medical School. An authorised registration slip will be provided by the Ethics Committee which should hotocopied and given to each student. This will state the Committee's recommendation on the safe time limit ore a subject is involved as a volunteer in another study.

NFORMED CONSENT: INADEQUATE OR INCOMPREHENSIBLE PATIENT INFORMATION IS THE COMMONEST SON FOR REJECTION OF PROJECTS BY THE ETHICS COMMITTEE See Guidelines document, Appendix 5.

consent be: WRITTEN ✓ VERBAL ✓ [illegible]

a patient information sheet be available? Yes see Appendix.

nsent is not thought to be required, state why, or explain any difficulty that might arise in obtaining consent.

sent will be sought in written form from at least one of the parents or guardians verbally from each of the children, after personal contact with the researcher.

ch copies of consent forms and information sheets (one for each of the 15 copies of the application form). ing Company forms, detach them from the full protocol and ensure that they are attached to this application.

F THIS IS A DRUG STUDY at what stage is this at its evaluation? Is the drug being supplied by a company a clinical trial exemption certificate or in response to an investigator with a clinical trial exemption.

te Clinical Trial Certificate (CTC) if relevant N/A

or Clinical Trial Exemption (CTX) number if relevant _____

F THIS IS A COMPANY SPONSORED TRIAL, are the investigators free to publish their results (subject to a onable period of consultation with the company)?

N/A

NSURANCE COVER

t arrangements have been made for insurance cover for subjects?

N/A

the company (if relevant) agreed to abide by ABPI's undertaking for ensation? Yes/No

HARMACY : The Pharmacy must be informed of any proposed drug trial. Specify what arrangements have made with Pharmacy regarding cost of drugs, willingness of Pharmacy to handle drugs and trial prescriptions, he mechanism of supply of drugs to patients. See Appendix 4 in the Guidelines.

N/A

lease confirm that you have sent a copy of the full protocol to the relevant Clinical Trial Pharmacist: please

of Pharmacist involved: ..... Date sent: .....

N/A

UBSTANCES TO BE ADMINISTERED :

COMMITTEE MUST BE INFORMED IMMEDIATELY OF ANY UNEXPECTED ADVERSE SIDE-EFFECTS

tance	Route	Amount	Frequency	Risks to subjects and others	Precautions	Desired effects	Side effects
s			N/A				

y form of radiation is to be used (e.g. x-rays, isotopes, heat, UV, laser, etc.) this form must be signed by the ation Protection Adviser (Mr. M. Fitzgerald, Department of Medical Physics, or Dr. D. Perkins, Department of nemistry, Medical School): or a separate letter may be attached.

ed : _____ Radiation Protection Adviser

dioisotopes are to be used then a DOH (ARSAC) Certificate is required.

of Certificate (if applicable) .....

ils of Isotopes etc

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rs (such
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icity)
n.14

WHAT WILL BE DONE TO SUBJECTS BECAUSE THEY ARE TAKING PART IN THE STUDY?

scribe BRIEFLY what will be required of the subject AND indicate anything extra to normal clinical management:
o risks to subjects and others and precautions.

ldren will be observed during venepuncture and children and parents will be erviewed about the child's illness. The questionnaires and observation schedule d are in general use and have been validated for the population in question.

Are any treatments or procedures being withheld which would otherwise be 'en?

None

venous samples: how, where, frequency, amount?

None

arterial samples: how, where, frequency, amount?

None

X-rays, radiation, ultrasonics, NMR Scanning, etc.?

None

biopsies, site, method, size, number?

None

anaesthesia, local or general?

None

other invasions such as cannulae, probes, catheters, endoscopies, lumbar nctures, electromyography?

None

non-invasive tests such as EEG, ECG, Nerve Conduction Studies?

None

psychological tests?

None

questionnaires? (see footnote[1])

Paediatric patients: Interview on coping (Spirito, 1988); Interview on understanding of illness; Interview on self esteem (Harter, 1985)

Parents: Interview on parental coping (McGubbin 1983); interview on family environment (Moos 1981

hospital admissions or outpatient visits

None.

other:

Observation of one venepuncture for each child

[1] 15 copies should be submitted UNLESS (a) the questionnaire is in general use (b) it has been validated or standardised for for the use and population in question. In this case only one copy need be submitted. A list of questionnaires considered to be in general use is kept in the Ethics Committee office. If a new questionnaire is being developed as part of the project the Committee may wish to see it before it is used.

OTHER RESOURCES : Will this project make use of hospital resources? No.

. beds, x-rays, scans, ECGs, blood tests, etc.? No

), which Departments?

e they been consulted?

v much will they cost?

), has this been negotiated for inclusion within the Research Grant?

HAVE YOU HAD STATISTICAL ADVICE (and if so, from whom?)

n preparing the protocol

Yes

n preparing the record sheet

No

n deciding the power of the study & number of subjects needed Yes, from the Maths and
atistics Department at the Institute of Education. The design will be a
ltivariate one and the statistical approach will include multiple regression and
g linear modelling.

GENERAL PRACTITIONERS :

e G.P. should be informed: please indicate -

At what stage the G.P. will be informed

Whether you intend to send the G.P. a copy of the Patient Information Sheet.

f you do not intend to inform the G.P., why not?

CONFIDENTIALITY :

What steps will be taken to safeguard the confidentiality of
ients' records?

Is the data going to be recorded automatically? If so it will be necessary to comply with the requirements of Data Protection Act[2].

~~x x Company sponsored trial x will the Comm. require access to the patients' notes (see Guidelines item 7) x x~~

ords and results will be kept separate from hospital records by the researcher. No
es or identifiable details will be written up and data files will be identified by
bers not by name.

circumstances where the researcher is sufficiently concerned about a child's emotional
l being, she would inform the appropriate member of the paediatric or psychology team
also discuss it with her research supervisor, Dr. Hindley.

---

[2] If in doubt contact the District Data Protection Co-Ordinator, Harewood House, 61, Glenburnie Road, SW17, if you work for the N.H.S. rector of Computing Services, St. George's Hospital Medical School, if you are employed by the University.

'AYMENT : ("See Research Involving Patients" pages 26/27)

'ill patients/subjects be paid for taking part in the study? [redacted]/No

If so, how much?

this cover the extra travelling expenses the investigation necessitates?

'ILL THE INVESTIGATORS RECEIVE GRANTS OR PAYMENTS FOR THE WORK DERTAKEN? (See "Research Involving Patients", pages 27-30) [redacted]/No

ES please state :

Vho is funding the investigation?

low much money will be provided?

low will the money be spent? Please list major items of expenditure, uipment, staff, investigations, etc.)

WHAT PROBLEMS MAY HINDER A SUCCESSFUL COMPLETION OF THE STUDY?

is may include ethical problems which may arise during the course of study).

None foreseen.

TES:

lodifications to the Protocol

or modifications in the course of the study should be re-submitted to the Committee for approval; minor nges should be reported to the Chairman. Please inform the Committee if the study is not funded or if it ninated prematurely: in the latter case, please explain why.

ollow-up

Medical Ethics Committee will conduct a follow-up on certain selected protocols within six months of the mencement.

dverse events of a serious or potentially serious nature should be notified to the administrator or a member of Ethics Committee within 24 hours. Phone numbers of all hospital members are kept by the switchboard ·ator at St. George's Hospital.

ıte of Submission : 28th August 1992

ɡnature of Investigator : Ursula Pretzlik

Print Name MRS URSULA PRETZLIK

ɡnature of Consultant,
P., Community Physician
Overall Charge: PE Hin

Print Name DR PETER HINDLEY

ST. GEORGE'S HOSPITAL

PATRONS:
HER MAJESTY THE QUEEN
H.R.H. THE DUCHESS OF KENT

BLACKSHAW ROAD,
LONDON, SW17 0QT.

Telephone: 081-672 1255

ext:

Your Ref:

Our Ref: DH/jlr/92.50.16

Received 8.10.92

2 October 1992

Mrs Ursula Pretzlik
Developmental Psychologist
MSc Child Development
Institute of Education
Department of Child Development and
Primary Education
20 Bedford Way
London WC1H 0AL

Dear Mrs Pretzlik,

Life threatening illness in children: understanding and coping

The Ethics Committee of 30 September, considered your protocol and was concerned about two points.

Firstly, members wondered whether younger children would be able to cope with the vocabulary and concepts included in the various questionnaires. Secondly, some members felt that the interviewing procedure was somewhat intrusive, given the severe nature of the illnesses which these children have, and the natural parental concern that will accompany it.

Members felt that it would be helpful if you could attend to answer questions in person and I would therefore be grateful if you could come to the next meeting on 4th November 1992. Could you please arrange a mutually convenient time with the Ethics Committee secretary on Ext. 52182.

Yours sincerely

David Hall
Secretary
Local Research Ethics Committee

cc Dr P. Hindley.

Department of Child Development and Primary Education

Chair Angela Hobsbaum
Professor Kathy Sylva

Direct Line 071-612 6219

INSTITUTE OF EDUCATION
UNIVERSITY OF LONDON

20 BEDFORD WAY
LONDON WC1H 0AL
Telephone 071-580 1122
Fax 071-612 6230

Director SIR PETER NEWSAM
Deputy Director PROFESSOR PETER MORTIMORE

December 1992

Dear Parents or Guardians,

I am conducting a study at St George's Hospital to find out more about children's understanding of illness and the way they cope with it. To do this I will be asking children to help me fill in two questionnaires and each of the children will also be observed, for a few minutes, during medical treatment. Knowing more about children's understanding of illness and the way they cope will help doctors and nurses to give better care to children in the future.

I will be visiting the ward regularly and on two occasions will go through the questionnaires with each child. In addition to them answering the questions, I would like to talk to parents or guardians to find out more about the child and how he or she is affected by the illness.

The records will be kept by me, separate from the hospital notes, and will remain strictly confidential. Whether or not you participate in this study will have no effect on the care your child receives. You and your child may withdraw at any time. This study is independent of the hospital and has the consent of Dr Graham Davies and Dr Sarah Ball.

Many parents and children enjoy taking part in studies like this. A personalized booklet will be given to each child summarizing what they have done to help us understand illness from the child's view point.

If you and your child would like to participate please sign the slip below and either hand it to me personally or put it into the letter box provided on the ward. Should you have any questions about this research, don't hesitate to contact me. You can phone me at the above number or at home (071-937 0809).

Yours sincerely

Ursula Pretzlik

Ursula Pretzlik
Child Psychologist

The Local Research Ethics Committee has approved the above statement.

The ~~Chair~~ Secretary of the Committee:

Date: 17/12/92

CONSENT GIVEN BY PARENT(S) OR GUARDIAN(S):

I (we) am willing for my child and myself to take part in Ursula Pretzlik's study on children's understanding and coping with illness. I know that all records will be confidential and that my child and I may decide to withdraw from the study whenever we wish. We will be informed of the findings.

Signed: .....

Boy or Girl's Name: .....

Date: .....

PLEASE return this slip to Ursula or put it into the letter box on the nurses' desk. THANK YOU !

9th December 1992

Dr David Hall
Local Research Ethics Committee
St George's Hospital
Blackshaw Road
London SW17 0QT

Dear Dr Hall,

Life threatening illness in children: understanding and coping

I am very pleased to know that the ethics committee has agreed for my project to go ahead. I look forward to starting as soon as possible.

Enclosed you will find an information sheet for parents concerning my proposed research. Don't hesitate to suggest alterations should you feel that they are necessary. Following the committee's recommendation the age limit has been changed from five years to seven years. I hope that this meets with your approval.

Please also find enclosed the original parent consent form which I would be most grateful if you could sign.

Yours sincerely

Ursula Pretzlik

ST. GEORGE'S HOSPITAL

PATRONS:
HER MAJESTY THE QUEEN
H.R.H. THE DUCHESS OF KENT

BLACKSHAW ROAD,
LONDON, SW17 0QT.

Telephone: 081-672 1255

ext:

Your Ref:

Our Ref: DH/CL/92.50.16

5th November, 1992

Mrs. Ursula Pretzlik,
Developmental Psychologist,
Institute of Education,
Department of Child Development and
Primary Education,
20, Bedford Way,
London, WC1H OAL.

Dear Mrs. Pretzlik,

Life threatening illness in children: understanding and coping

The Ethics Committee discussed your project further after your visit and agreed that this could go ahead, subject to an increase in the lower age limit at which you would include your subjects,

The Committee would like you to prepare an information sheet for parents explaining about the study.

Yours sincerely,

David Hall
Secretary
Local Research Ethics Committee

Mr Oliver Berman
Group Headquarters
St Bartholomew's Hospital
Smithfield
London EC1A 7BE

30 June 1993

Dear Mr Berman,

Re: 'Life threatening illness in children: understanding and coping'

Enclosed you will find 25 copies of my application for ethical approval. I understand that the next meeting will be on Friday, 16 July, 1993. Please do not hesitate to contact me at the above address or at home: 44, Hornton Street, London W8 4NT, Tel 071 937 0809 should you need to.

I look forward to hearing from you, with very many thanks.

Yours sincerely

Ursula Pretzlik,
Child Psychologist

Please read the notes attached to this form before preparing your submission.
The form must be completed fully and all necessary signatures obtained.

DISTRICT RESEARCH ETHICS COMMITTEE
City and Hackney District Health Authority

APPLICATION FOR ETHICAL APPROVAL

Title of Study: :Life threatening illness in children : understanding and coping

Consultant(s) in Charge of Study:: Prof. Tim Eden; Dr. Judith Kingston

3. a) Investigator(s):: Ursula Pretzlik, Child Psychologist
   b) Contact Name and tel.no. in the event of queries:: U. Pretzlik, 071-9370809 (home) or 071-6126226 (work)
4. Where will the Study be undertaken:: Ward and Out-patients, Paediatric Oncology
5. Signature(s) of Collaborators in the Study:
   (See attached notes)

6. a) Does the Study involve adult patients? ~~YES~~/NO **
   b) May the patients be children? YES/NO **
   (If so, please complete Child Patient Consent Forms)
7. a) Does the Study involve normal volunteers? ~~YES~~/NO **
   b) Payment to be made: — NA —
8. If the Study involves normal volunteers, will they be Bart's Medical Students? YES/NO/POSSIBLY **

— NA —

9. If the Study involves the use of any Drugs, please indicate their Licence Status with The Committee on Safety of Medicine:

— NA —

** (a) Freely available.
** (b) A Clinical Trial Certificate (CTC) has been issued (Please Attach Copy).
** (c) Exemption from requirement for Clinical Trial Certificate has been granted (Please attach a copy of the letter from DHSS).
** (d) Application for exemption from requirement for CTC has been made.
** (e) Healthy volunteer study - no application to CSM being made.

10. (a) Will the investigator(s) receive any personal fee in respect of this study? ~~YES~~/NO **
    Part of Ph.D. *
    (b) Has the Department of the investigator(s) received any financial contribution from a commercial concern connected with the proposed study, within the last 2 years, or will it in the foreseeable future? ~~YES~~/NO **
    (c) Has the principal investigator, or any member of his/her department acted as a paid advisor or consultant to a commercial concern connected with the proposed study? ~~YES~~/NO **
    (If YES, please attach details as specified in the attached guidelines)

** Delete as applicable.

I CONFIRM THAT I HAVE READ AND APPROVED THE ATTACHED PROTOCC

Signature of Consultant in Charge..... [signature]

Date..... 25/6/93

25 copies of this form, when completed, should be accompanied by 25 copies of a detailed protocol(guidelines for protocc enclosed) and the appropriate consent form(s) and returned to the Secretary of the District Research Ethics Committee, West Smithfield Gatehouse, St. Bartholomew's Hospital.
25 COPIES OF THE ENTIRE APPLICATION MUST BE SUBMITTED.

The Committee meets on the third Friday of each month (except August) and items for the agenda should be submitted by the 1st of the month in which you wish the project to be considered. Late applications will not normally be accepted.

June 1993

THE PROPOSAL

'Life threatening illness in children: understanding and coping'

Ursula Pretzlik

Abstract: The core of this study is quality of children's coping and its relationship to their cognitive understanding of illness and treatment. The nature and amount of parental support they receive are also being investigated. Fifty patients with aplastic anaemia or cancer, aged 7 to 16, boys and girls, are taking part. Interview and observational methods are being used to assess coping and understanding. Healthy children from the community will form a comparison group. It is hoped that the results of this study will improve the teaching of sick children about illness, the reason for their being admitted to hospital and the rationale for treatment. The research has been running smoothly for the past seven months at St George's Hospital, London and now it is being extended to St Bartholomew's Hospital, London.
Key words: children, illness, coping

Background and aim of the study

Coping is a process involving thoughts and behaviours within a specific context to master and/or tolerate stress. Lazarus and Folkman (1984) claim it includes 'all cognitive and behaviour efforts used to manage specific external and internal demands that are considered as taxing or exceeding the resources of the child'.

Age, experience, intelligence and gender contribute to an individual's way of coping (Melamed, Dearborn, & Hermecz, 1983; Sylva, 1991). Social context, which includes the family, school and hospital, also influence the children's coping. Families dealing with long term illness are no longer viewed as atypical, but as ordinary people in exceptional circumstances (Landsdown, 1988; Eiser, 1990). There has been a move away from the focus on mother/child support while at the same time reciprocal relationship between all family members are now taken into account (Dunn, 1992).

Previous work on children's understanding of a concept such as illness has relied heavily on Piaget's cognitive stage approach (1937). A new approach takes the social context into account (Woodhead, Carr & Light, 1991). The notion that children's knowledge about the world is organised in terms of 'schemas' or 'scripts' (Mandler, 1984; Nelson, 1986) is widely accepted. This study will be using the latter approach to measure what children know and how they describe the social context in which they learn about illness.

The main **aim** of this research is to look at the way children cope with life threatening illnesses through investigating some factors associated with the coping process.

This entails two linked hypotheses:

- The quality of children's coping is related to their cognitive understanding of illness and treatment.

- The quality of children's coping is related to the nature and amount of parental support they receive.

The concept of 'coping' is central to developmental theory, and clinical practice in the field of paediatric psychology (Compas, Wortham, & Ey, 1992). We need to know more about the relationship between coping and children's level of understanding of their illness. Results of this study will improve the teaching of sick children about their illness, the reason for the hospital admission and the rationale for treatment.

Similarly more detailed understanding of the relationship between parental support and coping may lead to improved practice on the part of doctors, nurses and counsellors in their work supporting families.

Plan of the investigation

The proposed research will be carried out as part of Ursula Pretzlik's PhD thesis under the supervision of Dr Peter Hindley, Senior Lecturer in Child and Adolescent Psychiatry, George's Hospital Medical School, London SW17 and Kathy Sylva, Professor in Child Development and Primary Education, Institute of Education, London WC1. It has the full consent of Tim Eden, Professor in Paediatric Oncology, St Bartholomew's Hospital, London EC1 and Dr Judith Kingston, Consultant in Paediatric Oncology, St Bartholomew's Hospital, London EC1.

Mrs Ursula Pretzlik, Developmental Psychologist, BSc Hons Psychology, MSc Child Development, Department of Child Development and Primary Education, Institute of Education, University of London, 20, Bedford Way, London WC1H OAL, Telephone: 071 580 1122, ex 6226, will be the investigator responsible for collecting data from the children and their parents or guardians on the ward and in out-patients.

This research is currently being carried out on the ward and out-patients at St George's Hospital, London. Formal permission was given (for 24 months) by the Wandsworth Health Authority's Ethics Committee in December 1992. Extending the research to St Bartholomew's hospital is vital to the success of the study.

Data gathering at St Bartholomew's Hospital should take no longer than eighteen months from the starting date and can begin as soon as formal permission has been given.

Methodology

Collecting data, using interview and observational methods, for each child takes place during three sessions. It is expected that parents will be present throughout unless the child prefers the interview in session II and III to be carried out with the researcher only.

Preliminary contact with the child and family takes place on the ward or during an out-patient visit. The researcher spends this first period with the patient playing and age-appropriate game, an opportunity to get to know each other.

Session I takes place during venepuncture. Immediately before, during and after the procedure. Here, the Observational Scale of Behaviour Distress, OSBD (Jay & Elliot, 1986; Sylva, 1992) is used. The child's behaviour is closely observed by the researcher and recorded in any of the ten categories on the checklist.

Session II takes place after the venepuncture observation, when the Kidcope questionnaire (Spirito, 1988; adapted for the UK by Pretzlik & Hindley 1993) is administered. A common problem is described by the child, then a venepuncture related problem, and finally a problem related to the patient's illness. Children respond by describing how they have dealt with each of these three problems.

Session III takes place during another visit by the researcher. Harter's Self Perception Profile for Children (1985) questionnaire is administered and the level of self-worth assessed. A semi structured interview related to the patient's understanding of his/her illness is carried our and recorded.

During sessions II and III two instruments will be administered to parents or guardians, the Coping

Health Inventory for Parents: an assessment of parental coping patterns (McCubbin, McCubbin, Patterson & Cauble, 1983; adapted for the UK by Eiser, 1990) and the Family Environment Scale, FES (Moos & Moos, 1981). These instruments explore parents' and guardians' coping strategies when faced with their child's life threatening illness.

Subjects

During a period of 18 months or less, it is anticipated that at least 30 paediatric patients will be studied.

The researcher will be in regular touch with the hospital staff and suitable subjects (children between 7 and 16 years with life threatening illness) will be recruited.

Agreement to take part in this study will be sought by the researcher from parents or guardians and the child, after confidentiality is assured. Parents will be given written information and asked to sign a consent form. Description of results will be passed on to the individual families and each child will receive a personalized booklet confirming his or her participation in the study.

Advice and cooperation from the Maths and Statistics Department at the Institute of Education has been and will be given. The Institute is well equipped and able to give the appropriate support to research students.

Confidentiality

Records and results will be kept separate from hospital records by the researcher. No names or identifiable details will be written up and data files will be identified by numbers, not by names.

In circumstances where the researcher is sufficiently concerned about a child's emotional well being, she would inform the appropriate member of the paediatric or psychology team and also discuss it with one of her researcher supervisors, Professor Kathy Sylva or Dr Peter Hindley.

CHILD PATIENT CONSENT FORM (for children under 12 years of age)

Consultant Prof T.Eden; Dr J.Kingston **Investigator** Ursula Pretzlik

Purpose of the study and brief description of procedure to be carried out

First I would like to introduce myself. I am a child psychologist doing research and am based at the Institute of Education which is part of the University of London. I am conducting a study at St Bartholomew's Hospital to find out more about children's understanding of illness and the way they cope with it. To do this I will be asking children to help me fill in two questionnaires and each of the children will also be observed, for a few minutes, during medical treatment.

Knowing more about children's understanding of illness and the way they cope will help doctors and nurses to give better care to children in the future. I will be visiting the hospital regularly and on two occasions will go through the questionnaires with each child. In addition to them answering the questions, I would like to talk to parents or guardians to find out more about the child and how he or she is affected by the illness.

is study has been explained to me and I understand:

) What the study involves
) That refusal to participate will not affect my child's treatment in any way
) That my child may withdraw at any time

therefore agree to take part in this study

nature of Patient's Parent(s).....Date.....

AVE BEEN PRESENT WHILE THE PROCEDURE HAS BEEN EXPLAINED TO THE PATIENT' ENT AND I HAVE WITNESSED HIS/HER CONSENT FOR HIS/HER CHILD TO TAKE PART IT.

nature of Witness.....N/A.....Date.....
e Witness should be a person not connected with the study)

l name and address of patient: .....

.....

.....

.....

CHILD PATIENT CONSENT FORM (for children of 12 years of age or over)

Consultant Prof T.Eden; Dr J.Kingston **Investigator** Ursula Pretzlik

urpose of the study and brief description of procedure to be carried out

First I would like to introduce myself. I work with children as a psychologist trying to find out more about children's understanding of illness and the way they cope with it. To do this I will be asking you to help me fill in two questionnaires and I will watch, for a few minutes, during your medical treatment.

Knowing more about children's understanding of illness and the way they cope will help doctors and nurses to give better care to children in the future. I will be visiting your hospital regularly and on two occasions will go through the questionnaires with you. In addition to answering the questions, I would like to talk to your parents or guardians to find out more about you and how you are affected by your illness.

s study has been explained to me and I understand:

What the study involves
That refusal to participate will not affect my child's treatment in any way
That my child may withdraw at any time

erefore agree to take part in this study

ature of Patient's Parent(s).....Date.....

VE HAD THE STUDY EXPLAINED TO ME AND I AGREE TO TAKE PART IN IT.

ture of Patient.....Date.....
over 12 years)

E BEEN PRESENT WHILE THE PROCEDURE HAS BEEN EXPLAINED TO THE PATIENT'S T AND I HAVE WITNESSED HIS/HER CONSENT FOR HIS/HER CHILD TO TAKE PART .

ture of Witness.....Date.....
Witness should be a person not connected with the study)

ame and address of patient: .....

.....

.....

....

Department of Child Development and Primary Education

Chair Angela Hobsbaum
Professor Kathy Sylva

Direct Line 071-612 6219

INSTITUTE OF EDUCATION
UNIVERSITY OF LONDON

20 BEDFORD WAY
LONDON WC1H 0AL
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Director SIR PETER NEWSAM
Deputy Director PROFESSOR PETER MORTIMORE

September 1993

ST BARTHOLOMEWS HOSPITAL: SOME INFORMATION

I am conducting a study to find out more about children's understanding of illness and the way they cope with it.

During regular visits to out-patients my plan is to observe each child for a few minutes during medical procedures/ treatment and to talk individually with them on two and possibly three occasions. During these talks I will ask questions about the child's understanding and coping with illness. These questions are designed for children from the age of 7 upwards and are phrased in 'child friendly' language.

I have found that children enjoy these talks a great deal and benefit from the opportunity to express some of their own ideas, experiences and feelings with an adult who is neither a family member nor involved with medical care. However, should the young patient at any time feel he or she would prefer not to continue with the session, the interview can either be postponed or stopped all together depending on the child's wishes.

In addition to the children answering questions, I would like to talk to parents or guardians to find out more about the child and how he or she is affected by the illness. The parents will be given information about the study together with a consent form. The records will be kept by me separate from the hospital notes, and will remain strictly confidential.

Should you have any questions about this research, don't hesitate to contact me at the above address or telephone me at home (071-937 0809).

Ursula Pretzlik
Child Psychologist, BSc(Hons) MSc

P.S. The Research Ethics Committee has given it's agreement for this study to go ahead. The study is independent of the hospital and has the consent of Professor Tim Eden and Dr Judy Kingston.

Department of Child Development and Primary Education

Chair Angela Hobsbaum
Professor Kathy Sylva

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Director SIR PETER NEWSAM
Deputy Director PROFESSOR PETER MORTIMORE

Mr Oliver Berman
Group Headquarters
St Bartholomew's Hospital
Smithfield
London EC1A 7BE

28 July 1993

Dear Mr Berman,

Re: Study 93/07/13 Life threatening illness in children: understanding and coping.

Enclosed you will find two copies of each of the two consent forms, one for you and one for Dr K.L. Costeloe. I have deleted the last paragraph as requested by the Local Research Ethics Committee and hope that these changes meet with the approval of the Chairman.

I look forward to hearing from you, with many thanks.

Yours sincerely,

Ursula Pretzlik,
Child Psychologist.

THE BARTS NHS GROUP

~~TRUST HEADQUARTERS~~

ST BARTHOLOMEW'S HOSPITAL,SMITHFIELD, LONDON EC1A 7BE
TELEPHONE: 071 601 8112

20th July 1993.

All correspondence should be sent to Oliver Berman at the above address.

Dr. U. Pretzlik,
Child Psychologist,
Institute of Education,
University of London,
20 Bedford Way,
LONDON WC1H 0AL.

Dear Dr. Pretzlik,

RE: STUDY 93/07/13: LIFE THREATENING ILLNESS IN CHILDREN: UNDERSTANDING AND COPING.

I am writing to confirm that the above study was considered by the Local Research Ethics Committee at their July meeting and in the course of discussion the following point was raised :

The last paragraph of the consent form should be deleted.

The Committee agreed to defer ethical approval. However, when the above points has been addressed the Chairman will be able to approve this study as ethically acceptable.

Yours sincerely,

DR. K.L. COSTELOE
CHAIRMAN, LOCAL RESEARCH ETHICS COMMITTEE.

CC: Professor T.Eden,
Department of Paediatric Oncology.

ROUP HEADQUARTERS
ARTHOLOMEW'S HOSPITAL
SMITHFIELD
)ON EC1A 7BE ENGLAND

THE BARTS NHS GROUP

GROUP HEADQUARTERS

ST BARTHOLOMEW'S SMITHFIELD,
LONDON EC1A 7BE
TEL: 071 601 8112/8434 FAX: 071 606 4790

Dr Vrsulai Pretzlik
Institute of Education
University of London
20 Bedford Way
LONDON
WCIH 0AL

All Correspondence should be sent to Oliver Berman at the above address

25 August 1993

Dear Dr Pretzlik

RE: 93/07/13: Life Threatening illness in Children : Understanding & Coping

Thank you for sending me copies of the consent forms that you are to use, amended as the Committee had requested. I am now able to approve this study as ethically satisfactory.

I would be grateful if you could inform all concerned with the Study of the above decision and if you would quote the above study number in any future correspondence related to this protocol.

Your Application has been approved on the understanding that you comply with the guidelines set by the Royal College of Physicians stating that all raw data concerned with the above study should be retained and be available for inspection for 10 years.

Yours sincerely,

K-h. Costeloe.

Dr. K Costeloe
Chairman, Local Research Ethics Committee

c.c Prof T Eden
Department of Paediatric Oncology

pretzlik.eth

GROUP HEADQUARTERS
BARTHOLOMEW'S HOSPITAL
SMITHFIELD
NDON EC1A 7BE ENGLAND

APPENDIX III

INFORMATION ABOUT THE CHILD AND THE FAMILY

SOME DETAILS ABOUT YOUR CHILD

CHILD'S NAME:

SEX:

DATE OF BIRTH:

TODAY'S DATE:

NAME OF SCHOOL:

YEAR AT SCHOOL:

DATE OF CURRENT HOSPITAL ADMISSION:

NAME OF ILLNESS:

PREVIOUS ADMISSIONS RELATED TO THIS ILLNESS:

DATE OF DIAGNOSIS:

PREVIOUS ADMISSIONS RELATED TO OTHER ILLNESS:

ADDRESS OF PARENT OR GUARDIAN:

LIVING WITH:
(eg. mother and father/partner,
father and partner,
guardian or other)

NAME OF SIBLINGS: DATE OF BIRTH: SEX:

SPECIAL PROVISION MADE BY THE FAMILY
DURING CURRENT HOSPITAL STAY:
(eg. relative looks after siblings,
father changes to night work)

OCCUPATION OF
MAIN CARE-GIVER:

OCCUPATION OF
MAIN CARE-GIVER'S PARTNER:

APPENDIX IV
THE KIDCOPE CHECKLIST

The Kidcope Checklist for Younger Children (Spirito *et at.*, 1991)

and

The Kidcope Checklist for Older Children (Spirito *et al.*, 1988)

an example

KIDCOPE FOR YOUNGER CHILDREN
AN ILLNESS RELATED PROBLEM

First Name: Date:

Birthday: Age: Boy or Girl

Instructions: I am trying to find out how children deal with different problems. Think of a time when you had a problem that bothered you. Can you describe this problem to me?

(1) Did that time (related to the above described problem) make you feel NERVOUS or ANXIOUS?

Not at all A little Somewhat A lot Very much

(2) Did it make you feel SAD or UNHAPPY?

Not at all A little Somewhat A lot Very much

(3) Did it make you feel CROSS or ANGRY?

Not at all A little Somewhat A lot Very much

Adapted for the UK by Ursula Pretzlik
Institute of Education, University of London

YOUNGER CHILDREN

Did you:	Yes	No	How much did it help? Not at all	A little	A lot
1) Try to forget it?					
2) Do something like watch telly or play a game to forget it?					
3) Stay on your own?					
4) Keep quiet about the problem?					
5) Try to see the good side of things?					
6) Blame yourself for causing the problem?					
7) Blame someone else for causing the problem?					
8) Try to sort out the problem by thinking of answers?					
9) Try to sort it out by doing something or talking to someone about it?					
10) Shout, scream or get angry?					
11) Try to calm yourself down?					
12) Wish the problem had never happened?					
13) Wish you could make things different?					
14) Try to feel better by spending time with others; family, grown-ups friends?					
15) Do nothing because the problem couldn't be solved?					

KIDCOPE FOR OLDER CHILDREN
THE BLOOD TEST

First Name: Date:

Birthday: Age: Boy or Girl

Instructions: I am trying to find out how children deal with different problems. Think of a time when you had a problem that bothered you. Can you describe this problem to me?

(1) Did that time (related to the above described problem) make you feel NERVOUS or ANXIOUS?

Not at all A little Somewhat A lot Very much

(2) Did it make you feel SAD or UNHAPPY?

Not at all A little Somewhat A lot Very much

(3) Did it make you feel CROSS or ANGRY?

Not at all A little Somewhat A lot Very much

Adapted for the UK by Ursula Pretzlik
Institute of Education, University of London

OLDER CHILDREN

Instructions: PLEASE read each item and choose a phrase that applies (if any). Next, answer the questions with a tick.	Did you do this?		How much did it help?		
	Yes	No	Not at all	A little	A lot
1) I thought about something else; tried to forget it and/or went and did something like watch the telly or play games to get it out of my mind.					
2) I stayed away from people; kept my feelings to myself and handled that time on my own.					
3) I tried to see the good side of things and/or concentrated on something good that could come out of it.					
4) I realized I brought the problem on myself and blamed myself for causing it.					
5) I realized that someone else caused the problem and blamed them for making me go through this.					
6) I thought of ways to solve the problem, talked to others to get more facts and information about the problem and/or tried to actually solve the problem.					
7 a) I talked about how I was feeling, shouted, screamed or hit something. b) I tried to calm down by talking to myself, going for a walk and/or I just relaxed.					
8) I kept thinking and wishing this had never happened, and/or that I could change what did happen.					
9) I turned to my family, other adults or friends to help me feel better.					
10) I just accepted the problem because I knew I couldn't do anything about it.					

APPENDIX V

THE OBSERVATION SCALE OF BEHAVIOUR DISTRESS

(Jay & Elliott, 1986)

The Observation Scale of Behavioral Distress
OSBD (1986)
Behavioral Definitions

Information Seeking (IS)

Definition:	Any questions regarding medical procedures
Examples:	"When will you stop?" "Is the needle in?" "Is the drip coming?"
Nonexamples:	"Will I get a toy?"

Cry (C)

Definition:	Crying sounds and/or onset of tears--usually non-intelligible but can be double coded with verbal categories.
Examples:	Sobbing Screnching up face--obvious onset of tears Booohooohoo Crying sounds Tears (code as long as still flowing and/or sounds)
Nonexamples:	Sniffling Heavy breathing

Scream (S)

Definition:	Loud vocal expression at high pitch/intensity, usually nonintelligible, but can be double coded with verbal categories. High pitch distinguishes this category from "Cry."
Examples:	Sharp, shrill, harsh, high tones Shrieks
Nonexamples:	Loud yelling but at low pitch

Restraint (R)

Definition:	Child must be physically held down by staff member or parent with noticeable pressure and/or child must be exerting force, resistance in response to restraint attempts by staff. Sometimes it is not clear if the child is exercising pressure back due to tightness of restraint (i.e., child cannot move). In such cases where restraint is obvious and child's resistance is not clear, code Restraint.

Verbal Resistance (VR)

Definition:	Any verbal expression of delay, termination, or resistance.
Rule:	Must be intelligible.

Examples:		
	"I want to go ..."	"Stop"
	"I want to go to the bathroom."	"No More"
	"No, No, No"	"Don't"
	"I don't like this."	"Let me rest"
	"Let me loose."	"Take needle out"
	"Take me home."	"I don't want it"
	"Don't hurt me"	

Emotional Support (ES)

Definition: Verbal or nonverbal solicitation of hugs, hand holding, physical or verbal comfort by child.

Rules: Code initiation only for physical behaviors.

Examples:
"Hold me"
"I love you"
"Momma" & "Daddy"
"Momma please"
"Help me"
Grabbing at others.
Reaching out to be held
(Do not code "Mommy" if part of statement is appropriate for another code, e.g., "Mommy, get me out of here"=Verbal Resistance, not Emotional Support.)

Verbal Pain (P)

Definition: Any words, phrases, or statements which refer to pain, damage or being hurt, or discomfort.

Rule: Must be intelligible. May be in any tense. Can be anticipatory as well as actual. Has to be a statement, not a question. This category is distinguished from "Cry" by coding discrete intelligible words as pain (Owh, ouch) and non-word crying sounds as "Cry." Only exception is that groans without crying are coded as Verbal Pain (Ahhh).

Examples:
"That hurt"
"It stings"
"Owwwh"
"Owwhee"
"You are killing me"
"You are pinching me"
"Oh!"

Nonexamples: "Will it hurt?" (=IS)

Flail (F)

Definition: Random gross movements of arms and legs or whole body. Flail often occurs in response to restraint. (Out-of-control behavior)

Rule: Must be random.

Examples:
Pounding fists
Kicking legs repeatedly and randomly
Throwing arms out repeatedly and randomly
Flapping arms on self or otherwise
Child's back moving back and forth repeatedly during procedure.

CODE SHEET

server _____ Name _____

te _____ Time _____

nfo. eking	Cry	Scream	Re-Strain	Verbal Resist	Emot. Supp.	Verbal Pain	Flail
IS	1 C	1 S	1 R	1 VR	1 ES	1 P	1 F
IS	2 C	2 S	2 R	2 VR	2 ES	2 P	2 F
IS	3 C	3 S	3 R	3 VR	3 ES	3 P	3 F
IS	4 C	4 S	4 R	4 VR	4 ES	4 P	4 F
IS	5 C	5 S	5 R	5 VR	5 ES	5 P	5 F
S	6 C	6 S	6 R	6 VR	6 ES	6 P	6 F
IS	7 C	7 S	7 R	7 VR	7 ES	7 P	7 F
IS	8 C	8 S	8 R	8 VR	8 ES	8 P	8 F
IS	9 C	9 S	9 R	9 VR	9 ES	9 P	9 F
IS	10C	10S	10R	10VR	10ES	10P	10F
IS	11C	11S	11R	11VR	11ES	11P	11F
IS	12C	12S	12R	12VR	12ES	12P	12F
IS	13C	13S	13R	13VR	13ES	13P	13F
IS	14C	14S	14R	14VR	14ES	14P	14F
IS	15C	15S	15R	15VR	15ES	15P	15F
IS	16C	16S	16R	16VR	16ES	16P	16F
IS	17C	17S	17R	17VR	17ES	17P	17F
IS	18C	18S	18R	18VR	18ES	18P	18F
IS	19C	19S	19R	19VR	19ES	19P	19F
IS	20C	20S	20R	20VR	20ES	20P	20F
IS	21C	21S	21R	21VR	21ES	21P	21F
IS	22C	22S	22R	22VR	22ES	22P	22F
IS	23C	23S	23R	23VR	23ES	23P	23F
IS	24C	24S	24R	24VR	24ES	24P	24F
IS	25C	25S	25R	25VR	25ES	25P	25F

APPENDIX VI

THE SELF-PERCEPTION PROFILE FOR CHILDREN

(Harter, 1985)

What I Am Like

ıe _____ Age _____ Birthday _____ Group _____
Month Day

or Girl (circle which)

SAMPLE SENTENCE

Really True for me	Sort of True for me				Sort of True for me	Really True for me
☐	☐	Some kids would rather play outdoors in their spare time	BUT	Other kids would rather watch T.V.	☐	☐
☐	☐	Some kids feel that they are very *good* at their school work	BUT	Other kids *worry* about whether they can do the school work assigned to them.	☐	☐
☐	☐	Some kids find it *hard* to make friends	BUT	Other kids find it's pretty *easy* to make friends.	☐	☐
☐	☐	Some kids do very *well* at all kinds of sports	BUT	Other kids *don't* feel that they are very good when it comes to sports.	☐	☐
☐	☐	Some kids are *happy* with the way they look	BUT	Other kids are *not* happy with the way they look.	☐	☐
☐	☐	Some kids often do *not* like the way they *behave*	BUT	Other kids usually *like* the way they behave.	☐	☐
☐	☐	Some kids are often *unhappy* with themselves	BUT	Other kids are pretty *pleased* with themselves.	☐	☐
☐	☐	Some kids feel like they are *just as smart* as as other kids their age	BUT	Other kids aren't so sure and *wonder* if they are as smart.	☐	☐
☐	☐	Some kids have *alot* of friends	BUT	Other kids *don't* have very many friends.	☐	☐

Really True for me	Sort of True for me				Sort of True for me	Really True for me
☐	☐	Some kids wish they could be alot better at sports	BUT	Other kids feel they are good enough at sports.	☐	☐
☐	☐	Some kids are *happy* with their height and weight	BUT	Other kids wish their height or weight were *different.*	☐	☐
☐	☐	Some kids usually do the *right* thing	BUT	Other kids often *don't* do the right thing.	☐	☐
☐	☐	Some kids *don't* like the way they are leading their life	BUT	Other kids *do* like the way they are leading their life.	☐	☐
☐	☐	Some kids are pretty *slow* in finishing their school work	BUT	Other kids can do their school work *quickly.*	☐	☐
☐	☐	Some kids would like to have alot *more friends*	BUT	Other kids have as many friends as they want.	☐	☐
☐	☐	Some kids think they could do well at just about any new sports activity they haven't tried before	BUT	Other kids are afraid they might *not* do well at sports they haven't ever tried.	☐	☐
☐	☐	Some kids wish their body was *different*	BUT	Other kids *like* their body the way it is.	☐	☐
☐	☐	Some kids usually *act* the way they know they are *supposed* to	BUT	Other kids often *don't* act the way they are supposed to.	☐	☐
☐	☐	Some kids are *nappy* with themselves as a person	BUT	Other kids are often *not* happy with themselves.	☐	☐
☐	☐	Some kids often *forget* what they learn	BUT	Other kids can remember things *easily.*	☐	☐
☐	☐	Some kids are always doing things with *alot* of kids	BUT	Other kids usually do things *by themselves.*	☐	☐

	Really True for me	Sort of True for me				Sort of True for me	Really True for me
1.	☐	☐	Some kids feel that they are *better* than others their age at sports	BUT	Other kids *don't* feel they can play as well.	☐	☐
2.	☐	☐	Some kids wish their physical appearance (how they look) was *different*	BUT	Other kids *like* their physical appearance the way it is.	☐	☐
3.	☐	☐	Some kids usually get in *trouble* because of things they do	BUT	Other kids usually *don't* do things that get them in trouble.	☐	☐
4.	☐	☐	Some kids *like* the kind of *person* they are	BUT	Other kids often wish they were someone else.	☐	☐
5.	☐	☐	Some kids do *very well* at their classwork	BUT	Other kids *don't* do very well at their classwork.	☐	☐
6.	☐	☐	Some kids wish that more people their age liked them	BUT	Other kids feel that most people their age *do* like them.	☐	☐
7.	☐	☐	In games and sports some kids usually *watch* instead of play	BUT	Other kids usually *play* rather than just watch.	☐	☐
8.	☐	☐	Some kids wish something about their face or hair looked *different*	BUT	Other kids *like* their face and hair the way they are.	☐	☐
9.	☐	☐	Some kids do things they know they *shouldn't* do	BUT	Other kids *hardly ever* do things they know they shouldn't do.	☐	☐
10.	☐	☐	Some kids are very *happy* being the way they are	BUT	Other kids wish they were *different*.	☐	☐
11.	☐	☐	Some kids have *trouble* figuring out the answers in school	BUT	Other kids almost *always* can figure out the answers.	☐	☐
12.	☐	☐	Some kids are *popular* with others their age	BUT	Other kids are *not* very popular.	☐	☐

Really True for me	Sort of True for me				Sort of True for me	Really True for me
☐	☐	Some kids *don't* do well at new outdoor games	BUT	Other kids are *good* at new games right away.	☐	☐
☐	☐	Some kids think that they are good looking	BUT	Other kids think that they are not very good looking.	☐	☐
☐	☐	Some kids behave themselves very well	BUT	Other kids often find it hard to behave themselves.	☐	☐
☐	☐	Some kids *are* not very happy with the way they do alot of things	BUT	Other kids think the way they do things is *fine*.	☐	☐

usan Harter, Ph.D., University of Denver, 1985

Master list of items grouped according to subscale.

Item # refers to the position on the child's form. Items keyed *positively* (+) present the *more* competent or adequate self-description as the first part of the statement, whereas items keyed *negatively* (–) present the *less* competent or adequate self-descrip ion first.

Item #	Keyed	
		SCHOLASTIC COMPETENCE
1	+	Some kids feel that they are very good at their schoolwork BUT Other kids worry about whether they can do the schoolwork assigned to them.
7	+	Some kids feel like they are just as smart as other kids their age BUT Other kids aren't so sure and wonder if they are as smart.
13	–	Some kids are pretty slow in finishing their schoolwork BUT Other kids can do their schoolwork quickly.
19	–	Some kids often forget what they learn BUT Other kids remember things easily.
25	+	Some kids do very well at their classwork BUT Other kids don't do well at their classwork.
31	–	Some kids have trouble figuring out the answers in school BUT Other kids can almost always figure out the answers.
		SOCIAL ACCEPTANCE
2	–	Some kids find it hard to make friends BUT Other kids find it's pretty easy to make friends.
8	+	Some kids have alot of friends BUT Other kids don't have very many friends.
14	–	Some kids would like to have alot more friends BUT Other kids have as many friends as they want. (New item).
20	+	Some kids are always doing things with alot of kids BUT Other kids usually do things by themselves.
26	–	Some kids wish that more people their age liked them BUT Other kids feel that most people their age do like them.
32	+	Some kids are popular with others their age BUT Other kids are not very popular.

Item #	Keyed	
		ATHLETIC COMPETENCE
3	+	Some kids do very well at all kinds of sports BUT Other kids don't feel that they are very good when it comes to sports.
9	–	Some kids wish they could be alot better at sports BUT Other kids feel they are good enough at sports.
15	+	Some kids think they could do well at just about any new sports activity they haven't tried before BUT Other kids are afraid they might not do well at sports they haven't ever tried.
21	+	Some kids feel that they are better than others their age at sports BUT Other kids don't feel that they can play as well.
27	–	In games and sports some kids usually watch instead of play BUT Other kids usually play rather than watch.
33	–	Some kids don't do well at new outdoor games BUT Other kids are good at new games right away.
		PHYSICAL APPEARANCE
4	+	Some kids are happy with the way they look BUT Other kids are not happy with the way they look.
10	+	Some kids are happy with their height and weight BUT Other kids wish their height or weight were different.
16	–	Some kids wish their body was different BUT Other kids like their body the way it is.
22	–	Some kids wish their physical appearance (how they look) was different BUT Other kids like their physical appearance the way it is.
28	–	Some kids wish that something about their face or hair looked different BUT Other kids like their face and hair the way it is.
34	+	Some kids think that they are good looking BUT Other kids think that they are not very good looking.
		BEHAVIORAL CONDUCT
5	–	Some kids often do not like the way they behave BUT Other kids usually like the way they behave.
11	+	Some kids usually do the right thing BUT Other kids often don't do the right thing.
17	+	Some kids usually act the way they know they are supposed to BUT Other kids often don't act the way they are supposed to.
23	–	Some kids usually get into trouble because of the things they do BUT Other kids usually don't do things that get them in trouble.
29	–	Some kids do things they know they shouldn't do BUT Other kids hardly ever do things they know they shouldn't do.
35	+	Some kids behave themselves very well BUT Other kids often find it hard to behave themselves. (New item).

Item #	Keyed	GLOBAL SELF-WORTH
6	–	Some kids are often unhappy with themselves BUT Other kids are pretty pleased with themselves.
12	–	Some kids don't like the way they are leading their life BUT Other kids do like the way they are leading their life.
18	+	Some kids are usually happy with themselves as a person BUT Other kids are often not happy with themselves.
24	+	Some kids like the kind of person they are BUT Other kids often wish they were someone else.
30	+	Some kids are very happy being the way they are BUT Other kids wish they were different.
36	–	Some kids are not happy with the way they do alot of things BUT Other kids think the way they do things is fine.

APPENDIX VII

THE COPING HEALTH INVENTORY FOR PARENTS

(McCubbin *et. al.*, 1983; Eiser & Havermans, 1992)

Coping with your child's illness

Each of the following describes different ways that people try to cope with a child's illness. Please rate each statement in terms of how much you find behaving in that way to be helpful or not.

	Not at all helpful				Very helpful indeed
Believing that my child will get better	1	2	3	4	5
Doing things with my child	1	2	3	4	5
Believing that things will always work out	1	2	3	4	5
Telling myself that I have many things I should be thankful for	1	2	3	4	5
Doing things with relatives	1	2	3	4	5
Believing in God	1	2	3	4	5
Taking good care of all the medical equipment at home	1	2	3	4	5
Believing that my child is getting the best medical care possible	1	2	3	4	5
Doing things together as a family (involving all members of the family)	1	2	3	4	5
Getting other members of the family to help with chores and tasks at home	1	2	3	4	5
Having my child seen at the clinic/ hospital on a regular basis	1	2	3	4	5
Believing that the hospital has my family's best interest in mind	1	2	3	4	5
Encouraging my child to be more independent	1	2	3	4	5
Involving myself in social activities (parties, etc.) with friends	1	2	3	4	5
Being able to get away from the home care tasks and responsibilities	1	2	3	4	5
Getting away by myself	1	2	3	4	5
Allowing myself to show my emotions	1	2	3	4	5
Buying gifts for my sick child	1	2	3	4	5

	Not at all helpful				Very helpful indeed
Concentrating on hobbies (art, music, jogging etc.)	1	2	3	4	5
Doing voluntary work outside the home	1	2	3	4	5
Becoming more self-reliant and independent	1	2	3	4	5
Keeping myself in shape and well groomed	1	2	3	4	5
Talking to someone about how I feel	1	2	3	4	5
Engaging in relationships and friendships which help me to feel important and appreciated	1	2	3	4	5
Entertaining friends in my home	1	2	3	4	5
Investing time and energy in my work or home	1	2	3	4	5
Talking with other parents in the same type of situation and learning about their experiences	1	2	3	4	5
Talking with the medical staff (nurses, social worker, etc.) when we visit the medical centre	1	2	3	4	5
Reading about how other people in my situation handle things	1	2	3	4	5
Reading more about the medical problem which concerns me	1	2	3	4	5
Explaining our family situation to friends and neighbours	1	2	3	4	5
Making sure prescribed medical treatments are carried out at home as necessary	1	2	3	4	5
Talking with the doctor about my concerns about my child	1	2	3	4	5

Scoring the Coping Health Inventory for Parents
revised by Eiser and Havermans (1992)

Subscale	Coping Pattern	Coping Items
1	Autonomy	10; 14; 15; 16; 17; 19; 20; 21; 22; 23; 24; 25; 26
2	Medical Care	1; 8; 11; 12; 13; 28; 33
3	Social Support/ Information	6; 27; 29; 30
4	Family Support	2; 3; 4; 5; 7; 9; 18; 31; 32;

APPENDIX VIII

THE FAMILY ENVIRONMENT SCALE

(Moos & Moos, 1986)

WHAT IT IS LIKE TO BE PART OF OUR FAMILY!

1. Family members really help and support each another.
2. Family members often keep their feelings to themselves.
3. We fight a lot in our family.
4. We don't do things on our own very often in our family.
5. We feel it is important to be the best at whatever you do.
6. We often talk about political and social problems.
7. We spend most weekends and evenings at home.
8. Family members attend church, synagogue, or Sunday School fairly often.
9. Activities in our family are pretty carefully planned.
10. Family members are rarely ordered around.

11. We often seem to be killing time at home.
12. We say anything we want at home.
13. Family members rarely become openly angry.
14. In our family, we are strongly encouraged to be independent.
15. Getting ahead in life is very important in our family.
16. We rarely go to the cinema, plays or concerts.
17. Friends often come over for dinner or to visit.
18. We don't say prayers in our family.
19. We are generally very neat and orderly.
20. There are very few rules to follow in our family.

21. We put a lot of energy into what we do at home.
22. It's hard to 'blow off steam' at home without upsetting somebody.
23. Family members sometimes get so angry they throw things.
24. We think things out for ourselves in our family.
25. How much money a person makes is not very important to us.
26. Learning about new and different things is very important in our family.
27. Nobody in our family is active in sports.
28. We often talk about the religious meaning of Christmas, Passover, or other holidays.
29. It's often hard to find things when you need them in our house.
30. There is one family member who makes most of the decisions.

31. There is a feeling of togetherness in our family.
32. We tell each other about our personal problems.
33. Family members hardly ever lose their temper.
34. We come and go as we want to in our family.
35. We believe in completion and 'may the best person win'.
36. We are not that interested in cultural activities.
37. We often go the cinema, sports events, camping, etc.
38. We don't believe in heaven or hell.
39. Being on time is very important in our family.
40. There are set ways of doing things at home.

41. We rarely volunteer when something has to be done at home.
42. If we feel like doing something on the spur of the moment we often just pick up and go.
43. Family members often criticize each other.
44. There is very little privacy in our family.
45. We always strive to do things just a little better the next time.
46. We rarely have intellectual discussions.
47. Everyone in our family has a hobby or two.
48. Family members have strict ideas about what is right and wrong.
49. People change their minds often in our family.
50. There is a strong emphasis on following rules in our family.

1/2 way

51. Family members rarely back each other up.
52. Someone usually gets upset if you complain in our family.
53. Family members sometimes hit each other.
54. Family members almost always rely on themselves when a problem comes up.
55. Family members rarely worry about job promotion, school marks, etc.
56. Someone in our family plays a musical instrument.
57. Family members are not very involved in recreational activities outside work or school.
58. We believe there are some things you just have to take on faith.
59. Family members make sure their rooms are neat.
60. Everyone has an equal say in family decisions.

61. There is very little group spirit in our family.

62. Money and paying bills is openly talked about in our family.

63. If there's disagreement in our family, we try hard to smooth things over and keep the peace.

64. Family members strongly encourage each other to stand up for their rights.

65. In our family, we don't try that hard to succeed.

66. Family members often go the library or to a book shop.

67. Family members sometimes attend courses or take lessons for some hobby or interest (outside of school).

68. In our family each person has different ideas about what is right or wrong.

69. Each person's duties are clearly defined in our family.

70. We can do whatever we want to in our family.

71. We really get along well with each other.

72. We are usually careful about what we say to each other.

73. Family members often try to one-up or out-do each other.

74. At home it's hard to be by yourself without hurting someone's feelings.

75. 'Work before play' is the rule in our family.

76. Watching T.V. is more important than reading in our family.

77. Family members go out a lot.

78. The Bible is a very important book in our house.

79. Money is not handled very carefully in our family.

80. Rules are pretty inflexible in our house.

81. There is plenty of time and attention for everyone in our family.

82. There are a lot of spontaneous discussions in our family.

83. In our family, we believe you don't ever get anywhere by raising your voice.

84. We are not really encouraged to speak up for ourselves in our family.

85. Family members are often compared with others as to how well they are doing at work or school.

86. Family members really like music, art and literature.

87. Our main form of entertainment is watching T.V. or listening to the radio.

88. Family members believe that if you sin you will be punished.

89. The washing up is usually done immediately after eating.

90. You can't get away with much in our family.

THE END

Thanks very much!

START HERE

T / F	1	2	3	4	5	6	7	8	9	10	True / False
T / F	11	12	13	14	15	16	17	18	19	20	T / F
T / F	21	22	23	24	25	26	27	28	29	30	T / F
T / F	31	32	33	34	35	36	37	38	39	40	T / F
T / F	41	42	43	44	45	46	47	48	49	50	T / F
T / F	51	52	53	54	55	56	57	58	59	60	T / F
T / F	61	62	63	64	65	66	67	68	69	70	T / F
T / F	71	72	73	74	75	76	77	78	79	80	T / F
T / F	81	82	83	84	85	86	87	88	89	90	T / F

THE END

Do not mark below this line

	C	Ex	Con	Ind	AO	ICO	ARO	MRE	Org	Cil
Rs										
Ss										

Form R Raw Score to Standard Score Conversion Table
(Normal Family Sample; N=1125)

Raw Score	Cohesion	Expressiveness	Conflict	Independence	Achievement Orientation	Raw Score
9.0	68	73	81	70	72	9.0
8.5	64	70	78	66	69	8.5
8.0	60	66	75	62	66	8.0
7.5	57	63	73	57	63	7.5
7.0	53	60	70	53	60	7.0
6.5	49	57	67	49	56	6.5
6.0	46	54	65	45	53	6.0
5.5	42	50	62	41	50	5.5
5.0	38	47	59	36	47	5.0
4.5	34	44	56	32	44	4.5
4.0	31	41	54	28	41	4.0
3.5	27	37	51	24	38	3.5
3.0	23	34	48	20	35	3.0
2.5	20	31	46	15	32	2.5
2.0	16	28	43	11	28	2.0
1.5	12	25	40	7	25	1.5
1.0	9	21	38	3	22	1.0
0.5	5	18	35	–	19	0.5
0.0	1	15	32	–	16	0.0

	Intellectual-Cultural Orientation	Active-Recreational Orientation	Moral-Religious Emphasis	Organization	Control	
9.0	70	70	72	70	76	9.0
8.5	67	67	69	67	73	8.5
8.0	64	64	67	64	70	8.0
7.5	61	62	64	61	67	7.5
7.0	58	59	62	59	65	7.0
6.5	55	56	59	56	62	6.5
6.0	52	53	56	53	59	6.0
5.5	49	51	54	50	56	5.5
5.0	46	48	51	48	54	5.0
4.5	43	45	49	45	51	4.5
4.0	41	43	46	42	48	4.0
3.5	38	40	44	40	45	3.5
3.0	35	37	41	37	43	3.0
2.5	32	35	39	34	40	2.5
2.0	29	32	36	31	37	2.0
1.5	26	29	34	29	34	1.5
1.0	23	27	31	26	32	1.0
0.5	20	24	29	23	29	0.5
0.0	17	21	26	20	26	0.0

APPENDIX IX

THE SEMI-STRUCTURED INTERVIEW ABOUT THE CHILDREN'S UNDERSTANDING OF THE ILLNESS

The interview formed a part of the data collection,

results are included in this thesis

(explanation in Section 4.4.4)

Ursula Pretzlik
August 1992

PROTOCOL FOR INTERVIEWING CHILDREN

An 'open' format is used to give the child the chance to answer in any way he/she chooses. The child will feel free to take as long as he/she wants on any question and may return to it later if he/she so wishes. The interview will be audio-taped to give the interviewer the opportunity to create a relaxed and unhurried atmosphere without taking handwritten notes.

At this stage in the study the interviewer and the child have built up a comfortable relationship. However, to instill confidence in working with the tape recorder some informal warm-up questions and answers will be followed by a replay of the tape to give the children the chance to hear themselves.

Objectives:

- To establish children's understanding of their illness.
- To describe how and from whom they gained knowledge about their illness.
- To explore if and how, in their opinion, information about their illness could be communicated in a better way.

Interview with the boy or girl:

'Can you tell me what (name of illness) is? Do you know what causes (name of illness)?'

'I know a boy/girl about a year younger than you are who has just found out that he/she has (name of illness).'

'If you met this boy/girl what would you tell him/her about (name of illness)?'

'And what would you tell him/her about the medical treatment you have been given here in the hospital?'

'If a child wanted to know more about the illness do you think that books or leaflets about (name of illness) would be a good idea? What if there was a video which showed a child with (name of illness)? What people, things and events should be in the video to help other children learn more about this illness?'

'Can you talk to your parents (or guardians) about the illness?' If yes - 'What do you talk about most?'

'Are you able to talk to anyone else about the illness?' If yes - 'What do you talk about the most?' 'What sorts of things would you like to know/find out?'

'Who would you like to tell you these things?'

'Some of the young men and women here (in the hospital) are learning how to be doctors. Many of them do not really know what it is like to have (name of illness). You know what it is like.'

> 'What could you tell them so that when they see a boy or a girl with (name of illness) they will have a pretty good idea what it's like?'

'Is there anything else you would like to tell me about your illness, something we forgot to talk about so far?'

At the end of the interview the child is given the chance of hearing the conversation (as a form of debriefing).